The clinical management of functional neurological disorder in UK health services: A mixed-methods study of diagnostic assessments and treatments, experiences, and perspectives

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Abstract

Background: Functional neurological disorder (FND) is a debilitating and disabling health condition. It is associated with a broad set of symptoms, and onset is typically spontaneous. The exact aetiology of FND is unknown, however there are several sociodemographic, neurobiological and psychological factors thought to be linked to its onset.

There has been little published evidence on how FND is clinically managed in the UK, or the experiences of patients, caregivers and healthcare workers on the associated diagnostic and treatment processes. This mixed-methods thesis aimed to establish the current UK clinical management of FND, and examine the experiences of healthcare workers, patients and caregivers on the diagnostic and treatment processes for FND.

Methods: A scoping review was conducted to identify current FND diagnostic assessments and treatments, alongside a comparison of current FND clinical guidelines. This was followed by an online survey to map the clinical management of FND in UK health services, and finally an interview study to explore the experiences of patients, caregivers and healthcare workers on the clinical management of FND.

Results: While there are a range of FND diagnostic tools and treatments, many do not have an evidence base reporting their effectiveness. The findings from this thesis highlight the high variability of service provision across the UK. Healthcare worker awareness of FND is limited, and instances of stigma and negative attitudes towards FND are still occurring in health services. Patient needs during the clinical management of FND were dismissed by healthcare workers.

Conclusion: This thesis has provided further support on the prioritisation of FND in UK services, and has revealed a great disparity across UK health services when supporting FND patients. The development of UK clinical guidelines, an effective education package and implementation of multidisciplinary teams are recommended, in order to improve the clinical management of FND.

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“You are going to be OK. You will get through this.

You’re not weird, you’re not a freak, and for Pete’s sake, you’re not faking this.”

- Berger (2015), p.10

Declaration

I declare that this thesis is a presentation of original work and I am the sole author. This work has not previously been presented for a degree or other qualification at this University or elsewhere. All sources are acknowledged as references.

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Chapter 1: Introduction

Functional neurological disorder (FND) has been documented under a variety of names for millennia (Trimble and Reynolds, 2016, van der Feltz-Cornelis and van Dyck, 1997) and is included in key medical manuals from both a psychiatric and a neurological perspective (World Health Organization, 2018, American Psychiatric Association, 2013). Yet researchers, academics and healthcare workers alike are still debating its meaning and sometimes even its very existence today. In the United Kingdom (UK), it is estimated that between 50,000-100,000 people have an FND diagnosis and approximately 8,000 diagnoses are made annually (Bennett et al., 2021, Carson and Lehn, 2016). While these numbers indicate that FND may be classed as a rare disorder (Department of Health and Social Care, 2021), it is the second most common reason to attend a neurology clinic (if a broad diagnostic category is used), only surpassed by headaches (Stone et al., 2010). Even though FND is commonly seen in health services, a limited amount of high-quality research conducted over the past 50 years, in conjunction with there being no official UK care guideline, have hindered the progression of diagnostic and treatment tools to effectively manage the condition (Espay et al., 2018).

To date, there has been little published evidence on how FND is clinically managed in UK health services. This is also the case for associated healthcare costs, and how FND patients navigate and experience these services. This doctoral thesis aims to address this knowledge gap by exploring the perspectives and experiences of patients, caregivers and healthcare workers on the clinical management of FND in the UK.

This introductory chapter describes the context and purpose of this research, followed by the current issues surrounding the clinical management of FND in the UK. The terminology used throughout the thesis and the structure of its content is discussed.

1.1 Classification of FND

Functional neurological disorder (FND) is a condition where a person experiences unexplained neurological symptoms that are not compatible with a neurological or medical condition upon medical examination (American Psychiatric Association, 2013). Throughout history, FND has been known by a variety of names, such as hysteria. The term ‘hysteria’ was changed to conversion disorder in the Diagnostic and Statistical Manual of Mental Disorders – third edition (DSM-3; American Psychiatric Association, 1980) and changed once again in the most recent DSM (DSM-5TR [updated in 2022]; American Psychiatric Association, 2013) to functional neurological disorder (FND)/conversion disorder (CD), which is becoming the most commonly used term to describe the condition in the United Kingdom (UK). In this thesis, the abbreviation FND will be used.

1.2 Clinical definitions of FND

FND is a disorder where a person experiences unexplained neurological symptoms that are incompatible with a neurological or medical condition (American Psychiatric Association, 2013). As there is no structural disorder present, the symptoms associated with the disorder are therefore classed as functional. FND encompasses functional movement disorders, paralysis, blindness and functional seizures (Fobian and Elliott, 2019). There is a broad range of FND symptoms which typically present with sudden onset; some of these include dystonia, dysphagia or abnormal gait (Stone et al., 2020), ranging from mild to severe. FND is a disorder with high levels of disability (Gelauff et al., 2014), with its symptoms comparable to other debilitating chronic conditions such as multiple sclerosis (Carson et al., 2011).

The DSM-5TR lists the following diagnostic criteria for FND:

- *"One or more symptoms of altered voluntary motor or sensory function.*
- *Clinical findings provide evidence of incompatibility between the symptom and recognised neurological or medical conditions.*
- *The symptom or deficit is not better explained by another medical or mental disorder.*
- *The symptom or deficit causes clinically significant distress or impairment in social, occupational, or other important areas of functioning or warrants medical evaluation."* (American Psychiatric Association, 2013, p.318)

It is important to note that the definition of FND and its diagnostic criteria differ between diagnostic manuals. Therefore, there is a risk that an FND diagnosis may be incorrectly given (or not given) due to the manual the healthcare worker has followed. This is particularly concerning as a delay in FND diagnosis may have a negative impact on clinical outcomes and prognosis (O'Keeffe et al., 2021). The International Classification of Diseases-11 (ICD-11; World Health Organization, 2018) labels FND as 'dissociative neurological symptom disorder', falling under the Mental, Behavioural or Neurodevelopmental Disorders umbrella. As there is a variance between DSM-5TR and ICD-11 terms, this thesis will follow the DSM-5TR guidelines.

The current DSM criteria differs from previous volumes, relying on the identification of positive symptoms rather than past psychological trauma or stressors (American

Psychiatric Association, 2013). Patients waiting for a diagnosis of FND face extensive delays, poor outcomes and the potential for iatrogenic harm (Espay et al., 2018).

1.3 Epidemiology and prevalence

FND is a heterogeneous condition with a predicted comorbidity neurologic disease rate of 10% (Carson and Lehn, 2016, Gilmour et al., 2020). Symptom onset is typically spontaneous; first symptom presentation usually occurs in adulthood, particularly between the ages of 35-50 years (Carson and Lehn, 2016). However, symptom onset can occur at any point during the lifespan (Bennett et al., 2021). The longevity of the disorder can be temporary or last for a large number of years (Gelauff and Stone, 2016). The prevalence rate of FND is 4-12 cases per 100,000 people (Carson and Lehn, 2016). While earlier studies reported a smaller rate for children (1.3 per 100,000; Ani et al., 2013 and between 2.3 and 4.2 per 100,000 cases; Kozlowska et al., 2007) a recent study reported a rate of 18.3 per 100,000 for children and adolescents aged between 5-15 years (Yong et al., 2023). While a precise rate cannot be currently calculated for adults in the UK (due to large epidemiological data not yet collected), studies have reported that approximately 8,000 FND diagnoses in the UK are given annually (calculated using a conservative incidence rate of 12 per 100,000 per year; Bennett et al., 2021). Unexplained medical symptoms make up almost 30% of referrals to neurology services, and 5% of patients in a general hospital setting meet the diagnostic criteria for FND (Folks et al., 1984), and 50 in 100,000 people experience FND within the community per year (Carson and Lehn, 2016). The misdiagnosis rate for FND is low; only 2-4% of patients are misdiagnosed with FND (Stone et al., 2005, Walzl et al., 2019). Although women are 2-3 times more likely than men to be diagnosed (American Psychiatric Association, 2013, Raynor and Baslet, 2019), the proportion of men affected increases in line with the age of onset (Bennett et al., 2021). A possibility for this large difference may be due to women presenting to outpatient care approximately 1.5 times more than men (Raynor and Baslet, 2019).

1.4 Aetiology

The exact aetiology of FND is unknown, however there are several sociodemographic, neurobiological, and psychological factors thought to be linked to the condition’s onset. Populations in developing nations or regions are more likely to have a diagnosis of FND, with prevalence rates reaching as high as 31% compared to developed countries (Encyclopedia of Mental Disorders, 2015). While this may be surprising (as it could be suspected that there would be fewer diagnoses made in developing countries due to a lack of health infrastructure), it can be speculated that a person in a developing country is more likely to receive an FND diagnosis due to them being more likely to experience adversities (Solberg and Peters, 2020) and later developing FND. People belonging to a lower socioeconomic status, living in rural areas or with limited education are more likely to be diagnosed with the disorder, as well as those who have psychological stress, psychological or neurological comorbidities, or have poor resilience skills (Testa et al., 2012). There is some evidence to suggest that psychological trauma and adverse childhood experiences have been linked to FND onset (Fobian and Elliott, 2019, Ludwig et al., 2018),. However, findings from studies researching the link between psychiatric stressors or comorbidities and FND have been inconsistent (Bowman and Markand, 1996, Salinsky et al., 2012, van der Hoeven et al., 2015). There are also physiological factors linked to the onset of FND, including illness exposure, excessive cortisol levels, chronic inflammation and biomarkers. Illness exposure, including both experiencing personal illness and being exposed to others experiencing an illness, has been reported as a risk factor of the onset of FND (Hotopf et al., 1999). Research has found 1 in 5 functional weakness patients had a limb injury before the onset of their functional condition (Stone et al., 2012), and many patients experienced a personal illness or physical event before FND onset (Wilshire and Ward, 2016). Regarding exposure to others experiencing medical events, it has been reported that more than one third of functional seizure (FS) patients have a family history of epileptic events (Lancman et al., 1993) and two thirds of FS patients had previously witnessed a seizure before FS onset (Bautista et al., 2008). Lastly, it has been speculated that people with mental health or neurological conditions, or those who have experienced past physical or psychological trauma, are more likely to develop FND (Nicholson et al., 2016a, Peeling and Muzio, 2022).

Recent research has explored the possibility of the onset of FND being triggered by the combination of a prior unexpected psychological or physical trauma event, and an increase in emotional arousal in the amygdala (Aybek et al., 2015). In addition, there has been recent speculation focused on how inflammation may play a role in the development of FND. Research suggests a link between stress-related events (such as trauma or adverse childhood events) and inflammation being induced by the immune system (Ratcliff and van der Feltz-Cornelis, 2020, Liu et al., 2017). If stress-related events are continuous and long-lasting, the inflammation experienced will become chronic. Although previous evidence has found that chronic inflammation is linked to the pathophysiology of stress-related disorders, the connection between the two has not yet been identified (Liu et al., 2017). Cytokines, a small peptide biomarker, are released by the immune system as a defence response to injury or infection, and certain cytokines are able to cross the blood-brain barrier (Banks et al., 1995) and may also damage or increase its permeability (Yarlagadda et al., 2009). There are different classes of cytokines, including anti- and proinflammatory cytokines (such as IL-1, TNF-α, and IL-6; Yarlagadda et al., 2009). This is of importance as specific cytokines can activate corticotropin-releasing hormones (CRH) which leads to the production of cortisol (the stress hormone; Raison et al., 2006).

If chronic inflammation is experienced, cytokines will be continuously released by the immune system and cause further cortisol to be produced, damaging the blood-brain barrier and allowing other biomarkers to cross it, leading to further issues. One study (van der Feltz-Cornelis et al., 2021) found elevated levels of TNF-α, IFNg, IL-6, IL-12, IL-17A, and lower levels of VEGF-α in FND with motor symptoms when compared to healthy patients, suggesting systemic low-grade inflammation and implication of the blood-brain barrier. Also, microRNAs involved in inflammation and vascular inflammation were correlated with cytokines VEGf-α and TNF-α, suggesting there is proof of concept for an epigenetic mechanism. Another study reported that damage to the blood-brain barrier could be a key difference between epilepsy and FS patients (Hamrah et al., 2020), supporting the notion of cytokines and chronic inflammation being a potential mechanism for FND. Other serum protein markers and biomarkers have also been associated with the condition, with research finding adrenocorticotropic hormone levels and Neuropeptide Y being the ideal combination of predictors for the onset of FS (area under the curve = 0.980; Miani et al., 2019).

1.5 Prognosis

A favourable FND prognosis is related to short symptom duration, age when receiving diagnosis, higher educational status, only having sensory symptoms, and employment status. However, disease comorbidity, longer duration of symptoms, taking unneeded prescription medications, lower health literacy and late diagnosis negatively affect prognosis (Fobian and Elliott, 2019, Gelauff et al., 2014, Brigham and Women's Hospital Inc., 2013, Gelauff and Stone, 2016). Indeed, it has been reported that a swift diagnosis followed by timely treatments are prudent for a positive prognosis (Aybek and Perez, 2022). However, Gelauff and Stone’s (2016) review on the prognosis of functional motor symptoms concluded that FND prognosis is generally poor, and low remission rates are observed when followed-up. Unfortunately, the average time from symptom onset to diagnosis is more than seven years (Reuber, 2009), leading to some FND patients facing a poor prognosis.

1.6 Health economic costs

Not only is FND a disabling and debilitating condition, it is also associated with large healthcare utilisation costs (Stephen et al., 2021). There are currently no healthcare costs associated with the United Kingdom, perhaps due to the limited research being conducted to establish the most appropriate or streamlined ways to diagnose and treat the condition, rather than focusing on the costs related with its clinical management. It has been estimated that the overall healthcare costs of FND in the United States of America is $900,000,000 USD annually (Stephen et al., 2019). In addition, healthcare utilisation costs to diagnose FND were reported to be approximately $26,468 AUD per patient in Australia (this figure includes costs associated with emergency room visits due to FND symptoms before diagnosis; Seneviratne et al., 2019) and €2,302 in Italy (Tinazzi et al., 2021) with over 50% of FND patients included in the Italian study being hospitalised before receiving their diagnosis. Interestingly, patients who received a clear and satisfactory FND diagnosis from a healthcare worker were more likely to have reduced health care costs. Lagrand and colleagues (2023) reported that patients who had received a poor diagnosis with limited explanation had an average total healthcare cost of $186,553 USD, whereas those with a more suitable diagnostic explanation had on average $117,133 USD in total healthcare costs (total costs include diagnosis and any treatments prescribed to each patient and are not an annual cost). A recent systematic review (O'Mahony et al., 2023) reported there is an excess annual cost (comprising both direct and indirect costs) linked to the condition (range: $4,964-$87,722 USD). However, these costs could be reduced by the use of active treatments by up to 90.7%.

1.7 Diagnostic assessments

Historically, diagnostic tests were completed to ‘rule-out’ other organic causes for the patient’s symptoms (such as epilepsy or stroke), rather than assessing if the patient’s symptoms are caused by FND. There is a development among neurologists to require positive signs for FND at neurological examination. However, this recommendation is not always being followed as it has been reported that even if healthcare workers (such as neurologists) are certain a patient is presenting with FND symptoms, further diagnostic tests are completed (Aybek and Perez, 2022).

Diagnostic appointments can be lengthy due to FND patients experiencing multiple symptoms at once, leading to more time needed for an effective assessment (Gilmour et al., 2020). Before undergoing any diagnostic assessments, it has been recommended that a detailed and thorough medical history is taken (Brigham and Women's Hospital Inc., 2013). The most common assessments used in the diagnosis of FND include positive clinical signs such as Hoover’s sign, which has been reported to be a reliable diagnostic method (Stone and Edwards, 2012) as well as neuroimaging techniques and videotelemetry electroencephalography (vEEG; Bennett et al., 2021). A review of the current diagnostic assessments is provided in Section 2.5.2.

1.8 Treatments/management of FND symptoms

As there is currently no cure for FND, treatment options are implemented to manage and alleviate the symptoms a patient is experiencing. Providing an in-depth diagnosis, and ensuring that positive features are clearly communicated, has been recommended as the first treatment in the clinical management of FND (Bennett et al., 2021) as it has been found that a clear and well explained diagnosis can reduce or even lead to the cessation of symptoms (Aybek et al., 2020). Common treatments to manage FND symptoms include physiotherapy (Nielsen et al., 2015), psychological therapies (such as psychotherapy; Bennett et al., 2021), psychoeducation (Aybek and Perez, 2022), occupational therapy (Bennett et al., 2021), cognitive behavioural therapy (Goldstein et al., 2020) and speech and language therapy (Duffy, 2016). Some treatments have been reported as more effective than others and currently, there is little evidence supporting pharmacological treatments for FND.

A small number of newer treatments are beginning to emerge, including hypnotherapy (Bennett et al., 2021), mindfulness-based therapy and prolonged exposure therapy (Aybek et al., 2020). A review of the current treatment options to manage FND symptoms is provided in Section 2.5.3.

1.9 Terminology

Due to the nature of this thesis, it is pertinent to describe the terminology which will feature throughout each chapter.

Although FND is now referred to as functional neurological disorder/conversion disorder in the DSM-5TR (American Psychiatric Association, 2013) and is generally the accepted term, FND patients may still receive a diagnosis of one (or more) of the following:

- Functional neurological symptom disorder (FNSD)
- Functional seizures or psychogenic non-epileptic seizures (FS / PNES)
- Functional movement disorder (FMD)
- Neurological conversion symptoms
- Dissociative neurological disorder or dissociative neurological symptom disorder (a term used in the ICD-11; World Health Organization, 2018)
- Functional weakness
- Conversion disorder (the alternative official term in the DSM5TR and the ICD-11; American Psychiatric Association, 2013, World Health Organization, 2018)

The different terms for FND have been scrutinised in recent times. A systematic review explored the preferred terms for the condition (using principles proposed for suitable terminology for medically unexplained symptoms) and found that the word ‘functional’ was not only the most popular with both patients and healthcare workers, but also the most acceptable label than other terms for the condition (Ding and Kanaan, 2017). Taking this study and the DSM-5TR criteria into consideration, the term functional neurological disorder (FND) will be used throughout this thesis.

‘Patients’, ‘caregivers’ and ‘healthcare workers’ are also terms which feature heavily throughout this thesis and therefore also need to be defined. ‘Patients’ refers to anyone who:

- Has received a diagnosis of FND
- Is currently undergoing diagnostic tests to determine whether they have FND, or
- Has been denied access to undergo diagnostic tests to determine if they have FND

‘Healthcare workers’ refers to any person employed in a health service who provides care and support to people with an FND diagnosis or suspected diagnosis. While working with patient and public involvement (PPI) members during the survey study development, the terms ‘clinician’ and ‘healthcare professional’ caused confusion, as some PPI members thought that the term ‘clinician’ only included doctors and others were not sure what the term ‘healthcare professional’ meant. The term ‘healthcare worker’ was suggested by PPI members as it is a simple and inclusive term for the wide range of people providing healthcare support for FND patients. Therefore, the term ‘healthcare worker’ has been utilised throughout this thesis.

The term ‘caregiver’ refers to a person who provides short- or long-term support for a person with a disability, illness or injury (Leslie et al., 2019). A caregiver can be paid or unpaid, and caregiving can be formal or informal. To ensure that there was no confusion when reporting support from healthcare workers and caregivers, the term ‘caregivers’ in this thesis refers to unpaid, informal caregivers.

1.10 Overview of the key issues

Functional neurological disorder is a disabling and debilitating health condition, leading to many diagnosed patients needing to medically retire or being unable to be employed due to the severity of their symptoms (Martin et al., 2003). Prognosis is generally poor, with patients from low socioeconomic status households, who are not highly educated, being more likely to have a poor prognosis than their counterparts (Bennett et al., 2021, Testa et al., 2012). This is particularly concerning as people belonging to a lower socioeconomic status with limited education are more likely to be diagnosed with FND (Testa et al., 2012). Although there have been many theories attempting to explain the cause of the disorder and onset of symptoms, a single cause has not been established. Therefore, diagnosing and clinically managing FND can be a challenging process as we do not have a full understanding of the aetiology relating to the condition. Historically, diagnostic tests were completed to 'rule-out' organic causes for the patient's symptoms (such as epilepsy or stroke) rather than simply assessing if the patient has FND. The rule-out diagnostic approach may lead to patients feeling frustrated as they undergo tests which may not lead to a diagnosis. The DSM-5TR recommends that healthcare workers utilise a 'rule-in' approach, ensuring they are assessing for positive signs (American Psychiatric Association, 2013). However, there are currently limited laboratory-based 'rule-in' diagnostic tools available to assist in a timely and accurate diagnosis, and healthcare workers are still likely to complete more diagnostic testing than needed (Aybek et al., 2020). Not only does this add extra burden to the patient undergoing diagnostic assessments, it also increases health utilisation costs in services.

FND is a difficult condition to clinically manage. Currently, there is no known cure for FND and effective treatment options to alleviate symptoms experienced by patients are limited. Even if symptoms are managed effectively, many patients experience relapses (Brigham and Women's Hospital Inc., 2013) or develop new FND symptoms spontaneously. There are only a handful of treatments that have been studied for effectiveness, using gold standard research methodology. These treatments include medication, psychotherapy, engagement with healthcare workers and accessing psychoeducational websites (Jafari et al., 2018, Drane et al., 2016, Gelauff et al., 2020, Goldstein et al., 2020, Hubschmid et al., 2015). Although new treatments are emerging, their effectiveness or safety when implemented, more high quality RCTs are needed. Patients receiving treatment may feel dissatisfied or exasperated by the available treatment options or may struggle with the notion that a '*cure*' has not been found. With the limited availability of FND-specific diagnostic tools and treatments, it is imperative that these tools and treatments are reviewed to ensure their accuracy and safety for patients.

Negative attitudes have enveloped FND throughout history. Even in recent times, FND patients have faced stigma from healthcare workers and even the general public, with beliefs that FND is not a 'real' condition, or that FND patients are malingering (Dosanjh et al., 2021, Robson and Lian, 2017). It has been reported that experiencing stigma and negative attitudes from healthcare workers has an impact on the likelihood of patients accepting their diagnosis, leading them to be less trusting of healthcare workers and less likely to engage with services and treatments (Fouche et al., 2019, Rawlings et al., 2017).

These outcomes have a negative impact on services and health utilisation costs; it has been found that patients supported during their diagnosis and received clear information, have a lower average overall health utilisation cost than those not well supported (Lagrand et al., 2023).

Although functional neurological disorder is a recognised condition in the DSM-5TR (American Psychiatric Association, 2013), at the time of writing this thesis there is no established National Institute for health and Care Excellence (NICE) clinical management guidance. Although not official guidelines, there are recent publications providing information on the management of FND symptoms (Alciati et al., 2020, Bennett et al., 2021, Gilmour et al., 2020). Additionally, an optimum clinical pathway document has been recently developed by a group of specialist healthcare workers (National Neurosciences Advisory Group, 2023), yet has not been implemented into the NHS. This lack of official guidance indicates that clinical management of FND in UK health services may vary. The lack of guidance may also impact on the shared decision process between patients and healthcare workers, who may be unaware of specific diagnostic pathways or treatments.

1.11 Purpose of the research

Although there are official FND clinical guidelines and formal clinical care pathways in other European countries, there are none based in the UK (perhaps due to the lack of evidence-based treatments for the condition). Therefore, NHS Trusts across the UK may be clinically managing FND differently from one another, or managing it ineffectively due to being unsure which diagnostic assessments or treatment options should be implemented. Understanding and establishing how FND is clinically managed across the UK is essential to improve the quality of care being provided to FND patients.

To date, there has been very little documentation of the perspectives and experiences of FND patients and their caregivers accessing health services across the UK. Similarly, there has been little research regarding UK-based healthcare workers' beliefs and attitudes on functional neurological disorder. Researching and documenting these perspectives, experiences and beliefs is imperative to ensure patients are able to access suitable and appropriate health care and support from well-informed healthcare workers. This is of great importance as FND patients typically have a poor prognosis and require ongoing support and management for their symptoms. In addition, it is important to fully understand how the FND diagnosis impacts both patients' and caregivers' lives and livelihoods.

Lastly, collating up-to-date evidence on how to clinically manage FND is prudent. As discussed previously, patients can present with a wide range of FND symptoms. Therefore, FND is not a ‘one size fits all’ condition, where only one treatment option can be used to manage symptoms effectively. By collating recent, high-quality evidence, we will be able to determine the effectiveness of current treatments and begin to explore how they can be implemented into services.

1.12 Aims and Objectives

The aim of this PhD study was to establish the current UK clinical management of FND and examine the experiences of healthcare workers, patients and caregivers on the diagnostic and treatment processes for FND by employing a mixed-methods approach. The objectives of this research are presented in Table 1.

Table 1: Research objectives

Objective	**Purpose of objective**	**Chapter addressing the objective**	**Potential impact of objective**
Provide an overview of the literature related to the clinical management of FND	At the time of study commencement, reviews synthesising FND literature were dated. In addition, there was no published evidence comparing international guidelines on the clinical management of FND. Therefore, a review was needed to identify and summarise up to date evidence on the diagnostic methods and treatment methods used in the clinical management of FND.	Scoping review (Chapter 2)	A review synthesising current evidence provides key stakeholders relevant information on the clinical management of FND.
Identify the tools and instruments used during the FND diagnostic process and treatments and interventions used to support a patient with FND in the UK	At the time of writing, there were no UK clinical guidelines for FND. Therefore, UK health services may be using different diagnostic assessment tools or treatment options from one another, or following out of date evidence in the clinical management of FND. These differences may have an impact on patient experiences or their clinical outcomes. Therefore, identifying the differences of the clinical management between UK services was needed.	Survey study (Chapter 4)	The potential impact of this objective is increasing awareness of the inequality of clinical management of FND across UK health services.
Identify patient needs during the diagnostic and treatment process for FND	Currently, the needs of FND patients accessing UK health services have not been documented. As it has been recommended that patient-centred care should be at the forefront of providing high-quality	Survey study (Chapter 4)	There is the potential to influence key stakeholders and services when providing FND care to patients.

Objective	**Purpose of objective**	**Chapter addressing the objective**	**Potential impact of objective**
	healthcare (The Health Foundation, 2016), it was important to identify and document these needs to ensure that patient needs are being met.	Interview study (Chapter 5) Key findings (Chapter 6)	
Explore the experiences of healthcare workers, patients and caregivers on the diagnostic and treatment processes for FND	There have been limited studies exploring the experiences and perspectives of healthcare workers, caregivers and patients on the clinical management of FND in the UK. Exploring the experiences involved in those working in, or accessing, FND services are crucial as we need to understand how attitudes and services are affecting healthcare.	Survey study (Chapter 5) Interview study (Chapter 6)	A greater understanding of the attitudes and beliefs of healthcare workers on the clinical management of FND, and understanding how patients and caregivers navigate and experience FND services in the UK.
Document the potential triggers for the onset of FND	Research has been conducted to establish the aetiology of FND, yet patient perspectives on their thoughts about what triggered the onset of their own diagnosis has not been readily studied. It is crucial to document these perspectives as the patient's lived experience may provide valuable insight into the condition that an outsider perspective may miss.	Survey study (Chapter 5) Interview study (Chapter 6)	Provide valuable insight into potential triggers to FND onset.

1.13 Structure of the thesis

The clinical background of FND, as well as issues surrounding the disorder leading to the rationale of this thesis, have been presented in this introductory chapter. A scoping review conducted to highlight the current diagnostic assessments and treatments used in the clinical management of FND, alongside an evaluation of current clinical guidelines for FND, is provided in Chapter 2. Chapter 3 describes the methods used to conduct the online survey and interview studies, as well as a section on reflexivity and a rationale for each research method utilised. Chapter 4 presents the findings from the online survey study and content analysis. In Chapter 5, the findings of the interview study are presented. In Chapter 6, the findings from the triangulation of the online survey and interview results are discussed. Finally, the findings from this work are presented in Chapter 7, alongside the implications for clinical practice, potential future research and next steps.

Chapter 2: Clinical management of functional neurological disorder: A scoping review of the literature

This chapter presents a scoping review of the clinical management of functional neurological disorder (FND). The review was conducted to establish the current diagnostic tools and treatments for FND, and compare clinical management guidelines. In addition, the literature was scoped to establish healthcare worker and patient perspectives of the clinical management of FND. This included how the FND diagnosis is communicated to patients and how often patients are involved in the process of managing their FND symptoms.

A narrative account of the results of the scoping review is provided; findings are summarised and recommendations for the clinical management of FND are considered.

Part of this chapter has been published in the Journal of Psychosomatic Research (Varley et al., 2023).

2.1 Evolution of the literature

Functional neurological disorder (FND) has been known by a variety of different names and has been recorded in documents as early as ancient Greece and Egypt (Trimble and Reynolds, 2016). Early historical documents detail the condition as a female disorder caused by the uterus 'wandering' around the body (van der Feltz-Cornelis and van Dyck, 1997). Between the 17th and 19th centuries, this view changed; clinicians began to theorise that the condition is linked to neuroses, the nervous system and the brain.

Case studies have been traditionally used to document the condition, with one famous case study being 'Dora', a patient diagnosed and treated by Sigmund Freud (Freud, 1905). There are many case studies focused on the clinical management of FND being published, and progress is being made in the effort to understand the aetiology and mechanisms of the condition.

The term 'hysteria' was changed to conversion disorder in the Diagnostic and Statistical Manual of Mental Disorders – third edition (DSM-3; American Psychiatric Association, 1980) and changed once again in the most recent DSM (DSM-5TR; American Psychiatric Association, 2013) to functional neurological disorder/conversion disorder. Over the past 10 years, numerous research studies (including cohort studies, observational studies, and randomised controlled trials [RCTs]) and reviews which focus on the condition have been published (such as Baslet et al., 2020, Martlew et al., 2014). These publications have assisted in identifying and examining potential diagnostic tools and treatments for FND.

However, only a handful of studies have focused on exploring the experiences and perspectives of FND patients and caregivers. Further, they provide limited results on the benefits and consequences of accessing healthcare. Therefore, future research and publications should not only focus on identifying the most effective diagnostic tools and treatments, but also on the experiences and perspectives of the individuals involved.

2.2 Rationale for Review

Diagnosing FND can be challenging both for the healthcare worker and patient. Laboratory-based FND diagnostic tools are limited. Historically, diagnostic tests were completed to rule-out organic possibilities for the patient's symptoms, based on neurological examination or imaging techniques (such as magnetic resonance imaging [MRI]). This process may have been frustrating for the patient as they were undergoing tests which may not have led to a diagnosis. As a reaction to this, rule-in approaches (where a specific test is used to support a diagnosis) are sought to positively diagnose FND. Therefore, this scoping review will investigate the current methods and tools used to diagnose FND.

Similarly, treatment options for patients with FND are limited, with only a handful of treatments being studied for effectiveness using an RCT design. These RCTs include:

- Investigating medication to treat FND symptoms (finding that intravenous haloperidol was significantly more effective in managing symptoms than midazolam; Jafari et al., 2018)
- Interdisciplinary psychotherapeutic intervention (IPI) vs care as usual (CAU) (reporting that IPI is statistically significantly in the improvement of psychological and physical symptoms and reduction in hospital stays; Hubschmid et al., 2015)
- Scripted diagnosis, psychiatry consultations and weekly follow-up calls (with scripted diagnosis and psychiatric consultation leading to a reduction in functional seizures, and weekly follow-up calls reducing seizures and improving mood; Drane et al., 2016)
- Educational websites and self-help websites vs CAU (finding no significant difference in the improvement of self-rated health from either website; Gelauff et al., 2020)
- Cognitive behaviour therapy (CBT) and CAU vs CAU (where no statistically significant difference was found between either group in the reduction of dissociative seizure frequency; Goldstein et al., 2020)

Patients and their family/caregiver receiving treatment may feel dissatisfied or exasperated by the available treatment options or may struggle with the notion that a ‘cure’ has not been found. Thus, a review into the available treatments and their effects is well-timed.

Currently, there is no established National Institute for health and Care Excellence (NICE) clinical management guidance, indicating that the clinical management of FND in UK health services may not be standardised. Although not official guidelines, there are recent publications providing information on the management of FND symptoms (Alciati et al., 2020, Bennett et al., 2021, Gilmour et al., 2020). The development of an optimum clinical pathway document has recently been drafted and finalised by a group of specialist healthcare workers (Edwards et al., 2019, National Neurosciences Advisory Group, 2023). This makes this scoping review timely as it will be able to consolidate current evidence that will be available for the development of future guidance.

It appears that there is a knowledge gap in this domain. A methodology that is often used to explore knowledge gaps in a research area is the scoping review (Peters et al., 2020, Tricco et al., 2016). This scoping review explored the body of literature and aimed to summarise the typical diagnosis and treatments, assess whether a shared decision-making process between healthcare workers and patients is occurring, and compare FND clinical management guidelines from other nations.

2.3 Aims & Objectives

This review aimed to scope the body of literature to investigate the clinical management of FND.

The objectives to the proposed review were to:

1) Provide an overview of the literature related to the clinical management of FND
2) Identify and summarise the different diagnostic methods used to diagnose FND
3) Identify and summarise FND treatments
4) Identify and compare international guidelines on the clinical management of FND
5) Summarise the experiences and perspectives of patients, caregivers and healthcare workers in the diagnosis and treatment of FND

2.4 Methods

Although systematic reviews are the ‘gold standard’ approach as they aim to appraise and synthesise empirical evidence reliably and accurately to answer a narrow clinical question (Liberati et al., 2009, Smith and Noble, 2016), scoping review methodology was more appropriate to answer the proposed question (Peters et al., 2020). The review’s question is presented in Section 2.4.1.

Scoping reviews aim to identify and map the current literature of a particular field, identify knowledge gaps and clarify key concepts, whereas a systematic review aims to synthesise data to inform clinical practice and research (Munn et al., 2018). This scoping review was informed by Arksey and O'Malley (2005) along with the Joanna Briggs Institute (JBI; Peters et al., 2020). The reporting was informed by the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR; Tricco et al., 2016). The scoping review protocol was registered with the Open Science Framework (Varley et al., 2021).

2.4.1 Stage 1: Identifying the research question

The first stage of Arksey and O'Malley's (2005) framework involves identifying the review's research question. After discussing the purpose of the review with the PhD supervisors, it was agreed that the review would focus on the following question:

How is Functional Neurological Disorder managed clinically?

Aims and objectives (detailed in Section 2.3) were then developed to ensure the research question was answered.

2.4.2 Stage 2: Identifying relevant studies

Typically, PICO (population/participants, intervention, comparator and outcome) criteria are used in systematic reviews to develop the inclusion and exclusion criteria, as it allows for key concepts to be included to answer the review's research question(s). However, Population/participants, Concept and Context (PCC), recommended by the Joanna Briggs Institute (2015) was followed for the current scoping review as it was a less restrictive alternative to identify the review's main concept (meaning the core idea that is being examined by the review). Outcomes were included in the Concept section (as recommended by the JBI, 2015). The review's PCC criteria (with a description of each part of the PCC mnemonic) is set out below.

2.4.2.1 Population

Population refers to specific participant, or population characteristics relevant to the review. Records (also known as studies or papers) which included participants/patients aged 18 years and older who either had an FND diagnosis, were undergoing the FND diagnostic process, or were receiving/had received treatment for one of the following conditions were eligible for inclusion:

- Conversion disorder (CD)
- Functional neurological symptom disorder

- Functional neurological disorder (FND)
- Functional movement disorder
- Neurological conversion symptoms
- Dissociative neurological disorder
- Dissociative neurological symptoms
- Functional seizures ([FS], including psychogenic seizures, psychogenic non-epileptic seizures [PNES] and non-epileptic attacks)
- Functional cognitive symptoms

It is important to acknowledge that some records may have been missed when running the search strategy due to studies using other terms to describe FND that are not listed above (such as hysteria) as they may be outdated terms, or terms not widely used in the literature or in clinical services.

2.4.2.2 Concept

The term concept, as an inclusion/exclusion criteria, refers to the core idea (or concept) that is being examined by the review. Therefore, the key concept of this review was to identify and summarise the clinical management of FND. Records which provided a detailed overview and/or evaluated patient involvement, shared decision-making, diagnostic processes or treatment of FND were considered for inclusion.

2.4.2.3 Outcomes

Although not a compulsory part of the PCC mnemonic, Outcomes can be a component of the review's 'Concept' (JBI, 2015). The outcomes for this review were:

- Diagnostic tests used
- Sensitivity and specificity of diagnostic tests (if applicable)
- Treatments used
- Treatment effects (if applicable)
- Health service provision of treatments
- Clinical management of FND

2.4.2.4 Context

Context refers to cultural factors (such as geographic location, gender or social factors) and specific settings (such as primary mental health care) that are relevant to the review. These factors are used to tighten the context of the review (such as only including high income countries or care provided in the emergency room).

The context of this review was:

- The clinical management of FND provided by health services (including both primary and secondary care)
- Ethnicity of patients/participants (if applicable)
- Income of country (low, medium and high)
- Geographic location

As there were no official UK government guidelines relating to FND at the time the scoping review was conducted, international guidelines were sought and compared.

In order to collect all information to address the knowledge gaps in this domain, all study designs (including qualitative and mixed-method studies), official government guidelines and healthcare websites were eligible for inclusion. Clinical trials including participants with an FND diagnosis were eligible for inclusion to gain a greater understanding of the diagnostic processes and treatment effectiveness.

A date limit for included records was implemented, as the focus of this review was concerned with the diagnostic tools and treatments currently being used in services. After discussions with the supervisory team, it was deemed that including records from the past ten years (September 2010-September 2020) would be suitable and appropriate, as the records would be focused on current diagnostic tools and/or treatments, and if including patients, will have used the DSM-IV or V criteria. While the JBI does state that placing a date limit on a search strategy may be implemented when a review's focus is concerned on recent innovations or interventions (The JBI, 2022), and it is common for scoping reviews to implement a date limit in their search strategy (Tricco et al., 2016), it must be noted that placing a date limit may mean that relevant studies (that are just outside of the date limit) are excluded. Further, it must be recorded that there is the potential for bias in a review if a search strategy is restricted (Helbach et al., 2022).

Records not written in English were translated where possible. If a translation were not possible, the record was excluded.

Due to the quantity of eligible level 6 or 7 evidence (editorials, anecdotes, ideas, opinions, case series and case reports), level 6 and 7 evidence has been reported in Appendix 1 and not in the main results.

2.4.2.5 Criteria for excluding studies (not covered in the inclusion criteria)

Records were excluded if data for different disorders were not separated. In addition, records that did not follow the DSM definition of FND (DSM-4, DSM-5 or DSM-5TR depending on time of publication) were excluded. This is because of the robustness of the

DSM criteria compared to other manuals (such as the ICD-11; World Health Organization, 2018).

2.4.2.6 Searches

Electronic database searches, hand searching reference lists and journals of relevant records, and a consultation exercise with experts in the field were conducted. Searches were conducted from 15.09.2020-17.09.2020 in four databases:

- Medline and Medline in Process
- PsycINFO
- Cochrane Database of Systematic Reviews (CDSR)
- Google Scholar

A comprehensive search strategy (Appendix 2) was developed based on guidance from an information specialist in the Centre for Reviews and Dissemination (based at the University of York). Records retrieved from the database searches were imported into EndNote X9 (The EndNote Team, 2013) and duplicates were removed. Remaining references were exported to Rayyan (Ouzzani et al., 2010), an online reviewing application for record sifting. Authors of publications that could not be obtained were contacted.

2.4.2.7 Consultation exercise

Previous research has stated that the contribution of relevant stakeholders can enhance a review’s results (Oliver, 2001). In line with this suggestion, and following Arksey and O’Malley’s (2005) recommendations, a consultation exercise was conducted in line with this scoping review. Patients, caregivers, experts and FND/CD networks were contacted via email and social media over a one-month period to contribute to the review by providing references to potentially relevant records. This included international clinical networks (such as the Functional Neurological Disorder Society, which comprises healthcare workers, scientists and researchers, students, and members of the public with an interest in FND/CD), relevant organisations (such as FND Hope UK), and patients and caregivers involved in FND research studies. The consultation exercise was also advertised on social media to reach relevant stakeholders outside of the listed organisations.

2.4.3 Stage 3: Study selection

2.4.3.1 Record Sifting

Two stages (title and abstract, then full paper) of record sifting occurred. It was originally planned that only two independent reviewers would assess the retrieved articles. However, due to ill health throughout the COVID-19 pandemic, five reviewers independently screened the titles and abstracts of all retrieved records. Each record was independently screened by two different reviewers. Full text publications were retrieved for potentially relevant records and then assessed by two independent reviewers. Due to the amount of potentially relevant records being assessed in the full paper stage (n = 709), it was planned that the second reviewer would assess 10% of the records (n = 72). After the 10% records were assessed, an inter-rater reliability test (Cohen's kappa; Cohen, 1960) was calculated.

Five questions were used to assess the relevance of articles:

1) Does the record contain information on a condition of interest?
2) Does the record contain information on FND diagnostic processes/methods or have a diagnostic focus of interest?
3) Does the record contain information on FND treatment process/interventions?
4) Does the record include information on FND clinical management or healthcare guidelines?
5) Does the record include information on FND patient involvement or the experiences and perspectives of patients, caregivers and healthcare workers in the diagnosis and treatment process of FND?

If the answer to the first question (and at least one of questions 2-5) was yes, the record was included. Disagreements were resolved by discussion or through a third reviewer.

To assess inter-rater reliability, a Cohen's kappa (Cohen, 1960) test was conducted for both sifting stages. There is a variety of guidance available to interpret the kappa test, including Altman (1997), Landis and Koch (1977) and McHugh (2012). Most kappa interpretation guidance is based on arbitrary benchmarks (Altman, 1997, Landis and Koch, 1977) and not on scientific study. A further issue with these benchmarks is that a 61% agreement can be seen as problematic (meaning that there is still a large disagreement between the reviewers) yet will still be classed as a 'good' (Altman, 1997) or 'substantial' (Landis and Koch, 1977) agreement. Several research articles recommend that 80% agreement is the minimum percentage for an acceptable inter-rater agreement (McHugh, 2012). Therefore, the guidance set out by McHugh and colleagues (2012) was deemed the most appropriate to follow due to its robustness.

It was agreed that if the Cohen's kappa calculation was at or above 0.8, it would be accepted. If the calculation was lower than 0.8, it was planned that the reviewers would discuss any disagreements, and then the second reviewer would assess a further 10% of the records (with another inter-rater reliability test being calculated). If this second calculation was still below 0.8, the reviewers would need to meet to explore possible reasons for the disagreements, and the author would assess the sifting criteria to ensure it was clear and understandable.

The percentage of agreement for the title and abstract stage was 89% (kappa calculation = 0.805, indicating a 'strong' inter-rater reliability; McHugh, 2012) and 92% (0.834) for the full paper sifting stage.

These calculations showed that the agreement between the reviewers was strong, and the sifting decisions were accepted at both stages.

For the title and abstract stage, the first and second reviewers both reviewed 33% of the records (n = 710) before the Cohen's kappa was calculated. This was because of the number of second reviewers at this stage. For the full paper sifting stage, 10% of the records were assessed (n = 72) by the first and second reviewers before the Cohen's kappa was calculated. As both Cohen's kappa calculations were accepted, the first reviewer continued to review the remaining records independently (title and abstract stage: n = 1,419, full paper sifting stage: n = 637).

Once the two sifting stages were completed, the data were then charted (detailed below).

2.4.4 Stage 4: Charting the data

2.4.4.1 Data Charting

Data charting, similar to data extraction, involves sifting and grouping relevant data into key themes relating to the review's aims and objectives (Arksey and O'Malley, 2005). It was planned that data would be charted and checked for accuracy by two independent reviewers. However, due to unforeseen issues (illness and care issues caused by the COVID-19 pandemic), data charting was completed by the author and then monitored and checked by the PhD supervisors.

A data charting form was developed in Microsoft Excel. This form was used to guide the data charting process, and ensure consistency of the data being charted. It was audited by the PhD supervisors. Examples of previous data charting forms were used as a guide to develop the form. The form was piloted on a small selection of studies (n = 20) and checked by the PhD supervisors. One minor amendment was made when piloting the form (a column was added to assess the usefulness of each included study). An example of a completed data charting form can be found in Appendix 3.

The following data were charted:

- Author(s) and year of publication
- Type of publication (e.g., RCT, review)
- Study aims
- Key findings
- Study methodology (if applicable)
- Outcome measure(s) (if applicable)
- Guideline type and summary (if applicable)
- Intervention/treatment type (if applicable)
- Disorder of interest
- Summary of patient involvement in decision process (if applicable)
- Participant/patient characteristics
- Setting (including country and type of service [if applicable])
- Study methods (including study design and recruitment methods)
- Study results
- Diagnostic method (if applicable)
- Study usefulness

2.4.4.2 Quality assessment

A quality assessment of eligible records was not conducted. This is because scoping reviews provide a narrative account of the body of literature and do not seek to assess the quality of the evidence (Arksey and O'Malley, 2005). However, a note was added to the data charting form on the quality of each study to support the data synthesis and theme development, which did influence the weight placed on the results of included studies.

2.4.5 Stage 5: Collating, summarising, and reporting results

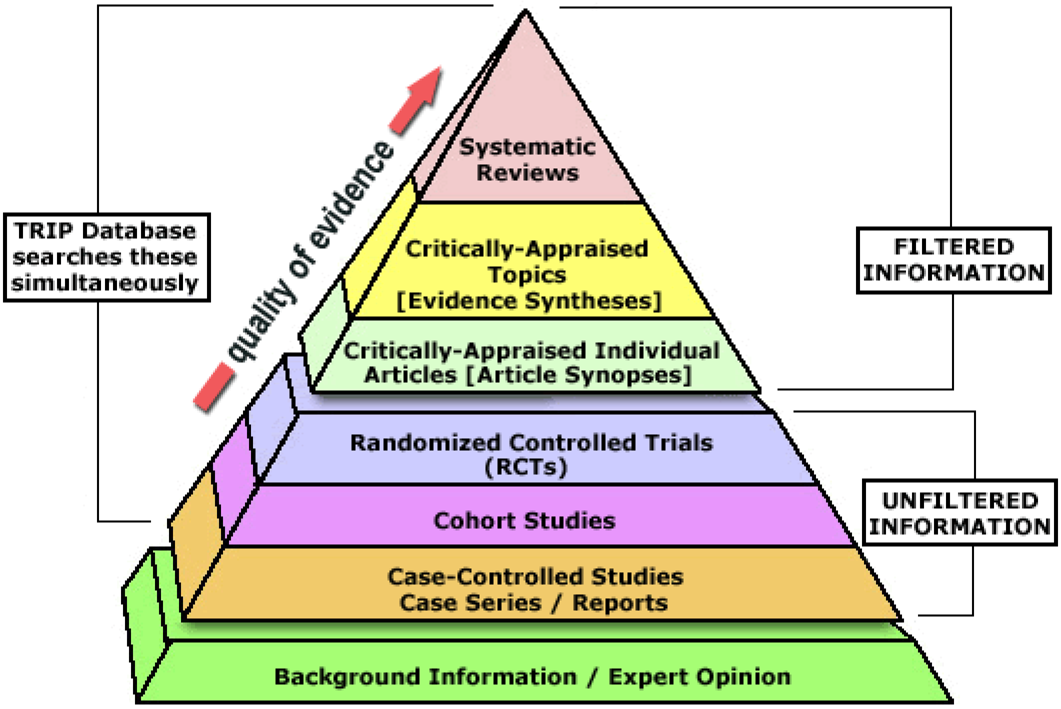
2.4.5.1 Data Synthesis

As discussed previously, scoping reviews aim to chart the literature on a specific topic or research area using a descriptive approach (Munn et al., 2018). Meta-analyses aim to consolidate data from a range of studies to provide precise information on treatment effects, effect sizes or other outcomes in a quantitative manner (Haidich, 2010). With this review aiming to provide an overview and summary of the clinical management of FND, it was deemed that conducting a meta-analysis for this review would not be necessary.

The charted data were collated and summarised. The synthesis identified key themes and issues, and also gaps in the current evidence that may inform future research. A descriptive numerical summary is reported below, which provides information on study characteristics. To minimise reporting bias, a template to record study characteristics (such as diagnostic/treatment type, sample size, outcomes reported) and findings was developed and used. This template was audited by the PhD supervisors and used to structure Tables 3-5. In addition to reducing bias, the tables provide a comprehensive review of the relevant records.

The hierarchy of research designs and evidence set out by Glover and colleagues (2006) has been used to order the relevant data. As shown in Figure 1, there are seven levels in the hierarchy, with opinions, case series and case reports in the lowest levels (due to being unscientific and a high risk of bias in their reporting), and critically appraised evidence and systematic reviews comprising the highest levels (due to their reliability). Level 6 and 7 evidence (editorials, anecdotes, ideas, opinions, case series and case reports) reporting on established diagnosis and/or treatment instruments have been reported in a table (Appendix 1) and not included in the thematic analysis (described in Section 2.6).

Figure 1: Hierarchy of research designs



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(Image from Glover et al., 2006, p.0)

A sub-analysis was conducted using thematic analysis (Levac et al., 2010). An iterative approach was used for the analysis. Eligibility was decided by the author using a question from the data charting form. Records were checked against the following question:

> *Does the record include information on FND/CD patient involvement or the experiences and perspectives of patients, caregivers or healthcare workers in the diagnosis and treatment process of FND?*

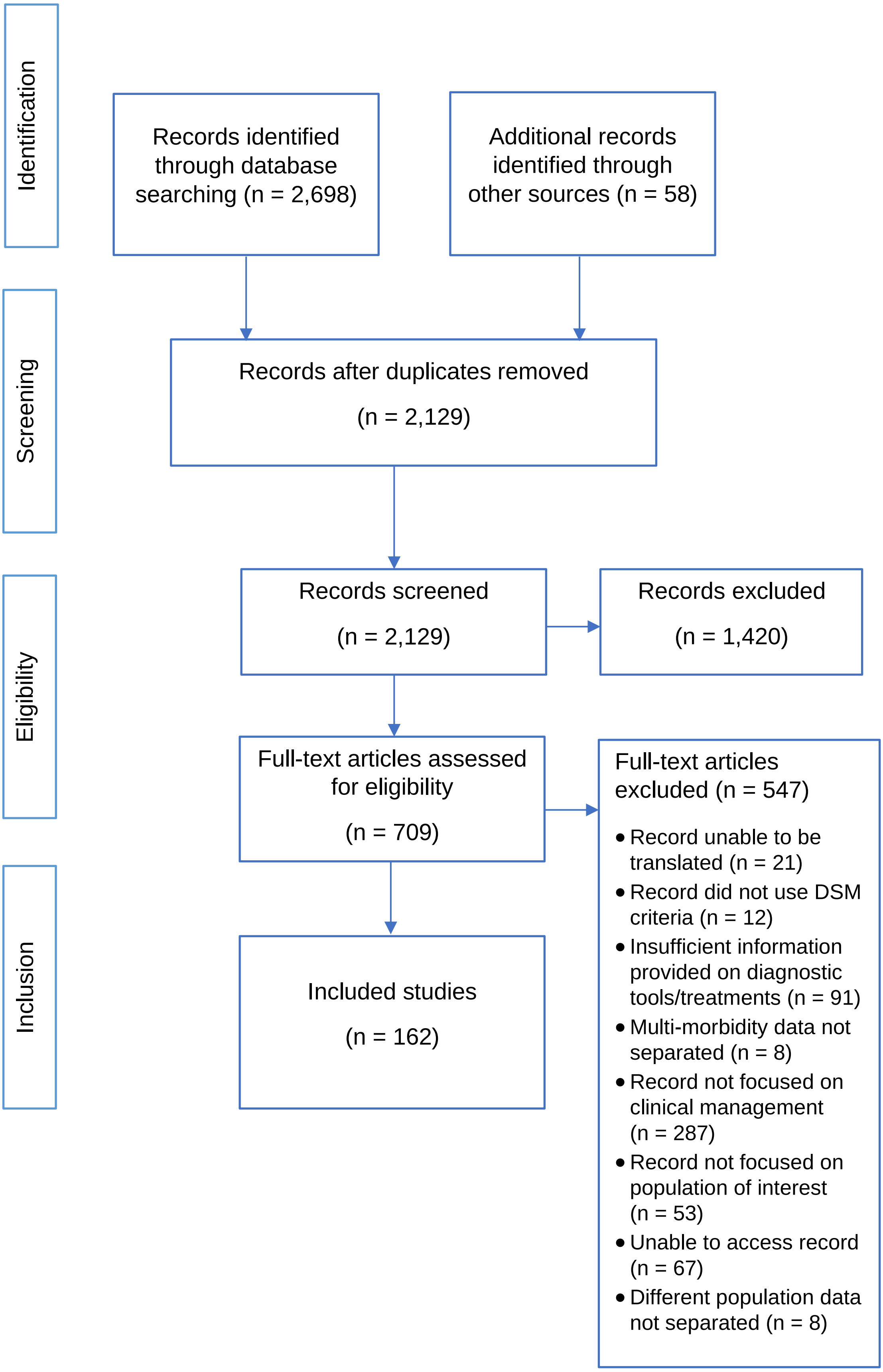
If the record met the criteria set out in the above question, it was included in the sub-analysis. In total, it was deemed that 48 articles met these criteria.

Each article was read three times to allow for familiarisation of the key concepts and content. After familiarisation, relevant data were charted verbatim from each eligible article to ensure that the original data and terminology used by each author was preserved. Once the data were charted for the relevant articles, the data were explored to study the key concepts and themes, and then coded using NVivo V.12 software. Concepts from each article were compared to the other eligible articles to assess commonality. The synthesis was conducted by the author, with another PhD researcher reviewing the theme development. The codes and themes were reviewed and reworked until they were finalised. The outcomes of the sub-analysis are reported in Section 2.6.

2.5 Results

The searches from the four databases identified 2,698 records (PsycINFO: 453, MEDLINE and MEDLINE In-Process: 573; Cochrane Database of Systematic Reviews [CSDR]: 20; Google Scholar: 1,652) and 58 records were retrieved through additional searches (handsearching, reference checking, and via the consultation exercise). 657 were duplicate records. 1,420 records were excluded at the title and abstract screening and a further 547 were excluded following full text screening. Reasons for exclusion are listed in the PRISMA diagram (Moher et al., 2015) below. A total of 162 records were relevant to the review and were included in the data charting and narrative reporting.

Figure 2: PRISMA diagram



2.5.1 Characteristics of the included studies

The below text reports data from all the relevant articles in the review (levels 1-7).

The literature (focused on the clinical management of FND) has increased considerably in recent times. Among the included studies (n = 162), 68% (n = 110) were published within the past five years of this review (2016-2020).

Five terms for the condition of interest were explored in the included records: functional seizures (FS; n = 68), functional neurological disorder (FND; n = 50), conversion disorder (CD; n = 26), functional movement disorder (FMD; n = 10), and functional neurological symptoms disorder (FNSD; n = 6).

The majority of studies reporting the country of setting (n = 87) were based in North America and Europe (29% and 48%, respectively). Research based in these continents were predominantly from the United Kingdom (26% of included studies) and the United States of America (25% of included studies). Following the World Bank definition of high-, upper-middle, lower-middle, and low-income countries (The World Bank, 2021), 86% of the included studies reporting geographical setting were focused on high-income countries, 7% focused on upper-middle-income countries, and 7% focused on lower-middle-income countries.

For the remainder of the results section, level 6 and 7 evidence (editorials, anecdotes, ideas, opinions, case series and case reports) will not be reported. A breakdown of the data included in these records (n = 38) are reported in Appendix 1. The included clinical guidelines are reported separately in Section 2.5.5.

The included studies used a variety of methods and study designs. The majority of included studies utilised a quantitative method (n = 53). Eleven studies used a qualitative design, and five used a mixed-methods approach. The remaining records were reviews. A breakdown of study designs is presented in Table 2, below.

Table 2: Breakdown of study designs

Study designs	**Total**
Review (systematic, literature, narrative)	47
Non-randomised study	19
Book or book chapter	11
Survey	9
Randomised Controlled Trial	7
Retrospective study	6
Interview study	6
Pilot study	5
Cohort study	4
Service evaluation	2
Consensus study	1
Cross-sectional study	1
Focus group study	1
Longitudinal Ancillary study	1
PhD thesis	1

Sixty-three studies reported a sample size. The average sample size across all studies was 102 (range = 4-1,146 participants, SD = 190.03). Five studies recruited healthcare workers (mean = 260.4, range = 4-1,146, SD = 497.63). Only 19 studies included more than 100 participants. Similarly, only 50% of included randomised controlled trials recruited more than 100 participants to their study.

Regarding research focus, 31 studies reported diagnostic methods used for FND, 45 reported FND treatments and interventions, while 25 focused on patient and healthcare worker perspectives on the clinical management of FND. Twenty-three studies reported on several of the aforementioned research focuses (for example, diagnostic methods and treatments).

Data has been separated by research focus. Included reviews are reported in Appendix 4. Included reviews are reported separately to ensure individual study findings are not duplicated throughout the results. A summary of the data charting for the included studies (ranked by evidence level) is reported in Tables 3-5.

Table 3: Summary of data charting for the included studies focused on FND diagnostic methods

Author	Country and setting	Study design	Study aims	Condition of interest	Sample size and population details	Diagnostic method	Main findings
Level 4 evidence							
Biberon et al., (2020)	France; Neurology department	Blinded prospective study	Evaluate the linguistic analysis in the differential diagnosis between FS and epilepsy	FS	Total sample size N = 32 FS patients (n = 13): Gender: F = 13, M = 0 Age (mean): 32.7 years Epilepsy patients (n = 19): Gender: F = 9, M = 10 Age (mean): 43.2 years	A semi-structured patient interview was used and assessed using conversational analysis	Two independent neurologists blindly assessed each interview. Rater 1 had a correct prediction rate of 84% and rater 2 88% correct prediction rate.

Author	**Country and setting**	**Study design**	**Study aims**	**Condition of interest**	**Sample size and population details**	**Diagnostic method**	**Main findings**
Daum et al., (2015)	Switzerland; Neurology Department	Pilot study	Establish the sensitivity and specificity of positive signs	CD	N = 40 CD group (n = 20): Gender: F = 9, M = 11 Age (mean): 37.4 years Control group (n = 20): Gender: F = 8. M = 12 Age (mean): 60.2 years	Positive signs	Six positive signs were found to be specific for CD and could be classified as 'highly reliable signs': (Specificity / Sensitivity) 1. Giveway weakness: 100% / 85% 2. Drift without pronation: 95% / 61% 3. Co-contraction: 100% / 30% 4. Splitting the midline: 100% / 42%

Author	Country and setting	Study design	Study aims	Condition of interest	Sample size and population details	Diagnostic method	Main findings
							5. Splitting of vibration sense: 88% / 50% 6. Hoover's sign: 100% / 76%
Level 5 evidence							
Daum and Aybek (2013)	Switzerland; Neurological Department	Prospective controlled study	Establish the sensitivity and specificity of the drift without pronation sign	CD	N = 54 CD group (n = 26): Gender: F = 17, M = 9 Age (mean): 41.1 years Organic illness group (n = 28): Gender: F = 14, M = 14 Age (mean): 62.9 years	Drift without pronation sign	Drift without pronation was observed in all (n = 26) CD patients and in only 7.1% of organic patients. Results revealed 93% specificity and 100% sensitivity.

Author	**Country and setting**	**Study design**	**Study aims**	**Condition of interest**	**Sample size and population details**	**Diagnostic method**	**Main findings**
Horn et al., (2017)	Switzerland; Hospital	Prospective study	Explore the specificity and sensitivity of sternocleidomastoid (SCM) and platysma motor signs	CD	N = 70 CD group (n = 30): Gender: F = 23, M = 7 Age (mean): 44.5 years Control group (n = 40): Gender: F = 14, M = 16 Age (mean): 65.4 years	SCM functional sign and platysma sign	Finding symmetrical platysma contraction, in conjunction with a weakness of head rotation, was a predictor of CD (95% specificity).
Laub et al., (2015)	USA; Hospital	Retro-spective study	Determine the diagnostic benefit of the huffing and puffing behaviours	FMD	FMD patients (n = 131): Gender: F = 96, M = 35	Healthcare worker observation: Three blinded healthcare workers rated standing and	Huffing and puffing–type behaviours generated a low sensitivity, but high specificity for an FMD diagnosis.

Author	**Country and setting**	**Study design**	**Study aims**	**Condition of interest**	**Sample size and population details**	**Diagnostic method**	**Main findings**
					Age at onset (mean): 41.5 years	walking videos for huffing and puffing behaviours.	
MacDonald et al., (2012)	Australia; Hospital	Prospective non-randomised study	Determine the accuracy of healthcare workers differentiating FS and epileptic seizures using videotaped events	FS	N = 27 Job title: • General physicians (n = 5), • General medical registrars (n = 7), • General medical residents (n = 7) • Psychiatrists (n = 8)	Healthcare worker observation: A questionnaire focusing on the given diagnosis, confidence in making the diagnostic decision, and an explanation on how the diagnostic decision was made.	55.4% of correct diagnoses were made when observing seizures via videotape. Neither the general medical or psychiatry group were particularly confident in reaching a diagnosis.

Author	Country and setting	Study design	Study aims	Condition of interest	Sample size and population details	Diagnostic method	Main findings
McWhirter et al., (2011)	UK; Hospital	Prospective unblinded cohort study	Determine the effectiveness of Hoover's sign for FND	FND	N = 124 Gender: F = 74, M = 50 Age (median): 77 years (range: 66-85)	Hoover's sign	Hoover's sign was found to be very specific (100%) and moderately sensitive test (63%) for FND patients with unilateral leg weakness.
Naganur et al., (2019)	Australia; Hospital	Prospective observational study	Investigate the accuracy of an ambulatory diagnostic system	FS	Patients with FS (n = 13): Gender: F = 9, M = 4 Age (median): 20 years	Automated ambulatory system	The system detected all epilepsy and FS from >661 hours of recording. Sensitivity and specificity for classifying FS were found to be 81.3% and 100%, respectively.

Author	**Country and setting**	**Study design**	**Study aims**	**Condition of interest**	**Sample size and population details**	**Diagnostic method**	**Main findings**
Nežádal et al., (2011)	Czech Republic; Neurology centre	Prospective non-randomised study	Evaluate the number of FS in patients with a refractory seizure disorder	FS	With FS (n = 111): Gender: F = 88, M = 23 Age (mean): 31.2 years	vEEG monitoring with suggestive seizure provocation	vEEG monitoring with suggestive seizure provocation support significantly contributed to an accurate FS diagnosis.
Syed et al., (2011)	USA; Epilepsy monitoring unit	Prospective study	Assess eye-witness reports of seizure semiology in FS prediction	FS	N = 35 No other details provided	Eye-witness reports of seizure semiology, vEEG	Signs that discriminate FS against epilepsy were found. It was also found that unreliable eyewitness accounts of semiology can hinder the prediction of FS.
Wegrzyk et al., (2018)	Switzerland; Hospital	Prospective study	Establish whether resting-state (RS)	FND	N = 48 FND group	fMRI scan	Results from that specificity,

Author	Country and setting	Study design	Study aims	Condition of interest	Sample size and population details	Diagnostic method	Main findings
			fMRI could discriminate FND patients from controls		(n = 23): Age (mean): 42.4 years Gender: F = 21, M = 2 Control group (n = 23): Age (mean): 42.4 years Gender: F = 22, M = 3		sensitivity and accuracy were over 68% (p = 0.004) to discriminate between the FND group and control group. The most discriminative connections included the prefrontal, amygdala, and sensorimotor regions, and the right caudate.
Asadi-Pooya (2016)	Iran; N/A	Survey	Investigate the opinions of neurologists about FS	FS	N = 18 Gender: F = 4, M = 14 Age (mean [± (SD)]):	Respondents reported using EEG, vEEG and serum creatine phosphokinase	There was a great variability in the approaches to the clinical management of FS.

Author	**Country and setting**	**Study design**	**Study aims**	**Condition of interest**	**Sample size and population details**	**Diagnostic method**	**Main findings**
					41.6 ± 7.5 years Years in practice: 8.9 ± 7.9 years (range: 1-30 years)	measurement for the diagnosis of FS.	
Foong and Seneviratne (2016)	Australia; Epilepsy monitoring unit	Retro-spective case review	Determine the ideal time of long-term video-electroencephalographic monitoring (VEM) to capture seizures in FS patients	FS	N = 108 No other details reported	VEM	When monitoring patients in a VEM program for up to one week, it was found that monitoring for five days yielded the greatest number of diagnostic seizures. It may be sufficient to diagnose up to 99% of FS patients.
Hingray et al., (2018)*	Survey completed	Survey	Examine the diagnosis and	FS	N = 1146	• Blood pressure recording	A relationship between access to

Author	Country and setting	Study design	Study aims	Condition of interest	Sample size and population details	Diagnostic method	Main findings
	across 63 countries; N/A		treatment of FS globally		(1098 healthcare workers completed the long survey, 48 completed the short survey) Age (median): 41-50 years (range: 21-80)	- Computed Tomography (CT) - ECG/EKG - EEG - Heart rhythm monitoring - Magnetic resonance Imaging (MRI) - Neuropsychological testing - Postictal prolactin measurement - Tilt-table examination	income, access to diagnostic tests and expertise was found.
Meppelink et al., (2016)	Not reported	Retro-spective cohort study	Examine the effectiveness of Bereitschaftspotential (BP) as a diagnostic tool	FMD	N = 29 FMD (n = 20): Gender: F = 10, M = 10 Age (mean): 44 years	BP	BP was only present in five of the FMD patients (25%; p = >0.05), whereas 13 patients showed a significant event-

Author	Country and setting	Study design	Study aims	Condition of interest	Sample size and population details	Diagnostic method	Main findings
					Control (n = 9): Gender: F = 3, M = 6 Age (mean): 48 years		related desynchronisation (ERD; p = <0.001). BP and ERP were not detected in the control group.
Tong et al., (2018)*	China; N/A	Survey	Provide an overview of clinical management services for FS patients in China	FS	N = 102 Gender: F = 62, M = 40 Age: 21–30= 28 31–40= 53 41–50= 15 51–60= 6	• CT scan • EEG • MRI scan • Neuropsychological testing • Postictal prolactin measurement • Routine heart recording • Tilt-table examination • vEEG	Diagnostic tools and interventions for FS in China are lacking. Hospitals in urban settings were equipped to clinically manage FS, however, more than half of the survey participants stated they would not make the FS diagnosis.

Author	Country and setting	Study design	Study aims	Condition of interest	Sample size and population details	Diagnostic method	Main findings
van der Feltz-Cornelis et al., (2020)	The Netherlands; Tertiary mental health centre	Cross-sectional observational design	Explore the frequency of FND/CD misdiagnosis	FND	N = 73 Confirmed FND (n = 64): Gender: F = 51, M = 13 Age (mean): 43.14 years Misdiagnosed (n = 9): Gender: F = 7, M = 2 Age (mean): 41.33 years	FND predictors: • Demographic variables • Early childhood sexual abuse or trauma • Family history of FND • Medication use • Negative life events • Psychiatric and somatic comorbidity • Type and duration of FND	12% of the patients in the study were misdiagnosed. Diagnostic re-evaluations should be completed for chronic FND cases.
Varone et al., (2020)	Italy; Regional Epilepsy Centre	Cross-sectional study	Identify a machine learning (ML) pipeline to categorise FS	FS	FS patients (n = 10): Gender: F = 8,	vEEG and EEG	It was found that FS and control discrimination tasks performed via the

Author	**Country and setting**	**Study design**	**Study aims**	**Condition of interest**	**Sample size and population details**	**Diagnostic method**	**Main findings**
			from healthy controls		M = 2 Age (mean): 28 years Controls (n = 10): Gender: F = 7, M = 3 Age (mean): 33 years		ML algorithm and validated attained an average accuracy of 0.97 (±0.013). The results suggest that the ML algorithm may be valuable in supporting existing FS clinical diagnosis.
(Walzl et al., 2019)	Scotland; Neurology centres	Multi-centre cohort study	To assess the frequency of functional disorder diagnosis better explaining original symptoms	FND	N = 2,378 (organic baseline diagnosis) No further details reported	Questionnaire on diagnostic change	Diagnostic errors were found in 48 patients, 10 of which had a functional diagnosis.

*Record reports more than one research focus so is present in multiple tables.

Table 4: Summary of data charting for the included studies focused on treatments

Author	Country and setting	Study design	Study aims	Condition of interest	Sample size and population details	Treatment/ intervention	Main findings
Level 4 evidence							
Cope et al., (2017a)	UK; Hospital	Pilot study	Test the effectiveness of a CBT-based psycho-education group on reducing FS frequency	FS	N = 25 Gender: F = 21, M = 4 Age: 18-25 = 5 26-35 = 8 36-45 = 8 46+ = 4	CBT-based psychoeducation group	The CBT group was found to be a valuable treatment for FS, with almost 40% of treatment completers being seizure free.
Dallocchio et al., (2016)	Not reported	Pilot RCT	Assess the feasibility and efficacy of CBT and adjunctive physical activity (APA) for FMD	FMD	N = 29 CBT + APA (n = 10): Gender: F = 4, M = 6 Age (mean): 33.7 years CBT alone (n = 11):	• CBT + APA (one hour session, twice-weekly) • CBT alone • Care as usual	Both intervention groups significantly improved over time vs. the control group). It was found that CBT was effective in improving FMD symptoms.

Author	Country and setting	Study design	Study aims	Condition of interest	Sample size and population details	Treatment/ intervention	Main findings
					Gender: F = 2, M = 9 Age (years): 34.7 years Care as usual (n = 8): Gender: F = 2, M = 6 Age (mean): 32.9 years		No favourable effect of APA was found.
Drane et al., (2016)	USA; Epilepsy monitoring unit	RCT	Evaluate common methods of FS clinical management	FS	N = 37 Standard practice (n = 12): Gender: F = 10, M = 2 Age (mean): 45.3 years	• Inpatient psychiatry consult • Scripted diagnosis • Weekly follow-up phone calls as well as inpatient psychiatry	Participants in the scripted diagnosis and psychiatric consultation group had a reduction in FS. Participants receiving weekly phone calls had a reduction in

Author	Country and setting	Study design	Study aims	Condition of interest	Sample size and population details	Treatment/ intervention	Main findings
					Structured Feedback (n = 10): Gender: F = 7, M = 3 Age (mean): 37.7 years Structured ongoing feedback (n = 15): Gender: F = 13, M = 2 Age (mean): 34.1 years	consultation and scripted diagnosis	seizures and improved mood.
Espay et al., (2019)	USA; Setting not reported	Pilot study	Evaluate the effectiveness of CBT on tremor severity and motor/ emotion-processing circuits in	FMD	N = 40 FMD (n = 12): Gender: F = 9, M = 3 Age (mean): 50.5 years	CBT (12, weekly CBT outpatient sessions)	It was found that CBT led to near or full remission in almost 75% FMD patients.

Author	Country and setting	Study design	Study aims	Condition of interest	Sample size and population details	Treatment/ intervention	Main findings
			patients with FMD		Control (n = 25): Gender: F = 21, M = 4 Age (years): 43.6 years		
Gelauff et al., (2020)	The Netherlands; Neurology centre	RCT	Establish the effectiveness of an educational and self-help website with care as usual (CAU) versus usual CAU only	FND	N = 186 Intervention group (n = 93): Gender: 73% female Age (mean): 48 years Control group (n = 93): Gender: 70% female Age (mean): 49 years	• An educational website with self-help components • CAU	The educational website was found not to be an effective treatment. No significant difference in self-rated health improvement at three months (44% vs 40%, p = 0.899) or six months (42% vs 43%, p=0.435) was reported.

Author	Country and setting	Study design	Study aims	Condition of interest	Sample size and population details	Treatment/ intervention	Main findings
Goldstein et al., (2020)	UK; Neurology and epilepsy centres	RCT	Compare the effectiveness of CBT with CAU versus CAU alone to reduce FS frequency	FS	N = 368 CBT + CAU (n = 186): Gender: F = 140, M = 46 Age (mean): 37.3 years CAU only (n = 182): Gender: F = 126, M = 56 Age (mean): 37.7 years	• CBT and CAU • CAU	No statistically significant difference was found between the CBT and CAU group versus the CAU only group for the main outcome, but most secondary outcomes showed improvement.
Hubschmid et al., (2015)	Switzerland; Neurology department	RCT	Compare a brief interdisciplinary psycho-therapeutic intervention (IPI) to CAU for FS	FS	N = 23 IPI (n = 11): Gender: F = 60%, M = 40% Age (mean): 37.57 years	• IPI • CAU	A statistically significant improvement of psychological and physical symptoms, and a reduction in new

Author	Country and setting	Study design	Study aims	Condition of interest	Sample size and population details	Treatment/ intervention	Main findings
					CAU (n = 12): Gender: F = 91%, M = 9% Age (mean): 31.53 years		hospital stays, were found in the IPI group.
Jafari et al., 2018	Iran; Emergency department	RCT	Compare the effects of midazolam vs haloperidol for CD patients	CD	N = 140 Midazolam group (n = 70): Mean age: 29.67 years Gender: F = 41, M = 29 Haloperidol group (n = 70): Mean age: 29.54 years Gender: F = 44, M = 24	• 2.5mg of IV haloperidol • 2.5 mg of IV midazolam	IV haloperidol was significantly more effective in managing CD than midazolam (91.5% vs 64.3%)
Ghanbarizadeh et al., (2018)	Iran; Hospital	RCT		CD	N = 144 Haloperidol	• IV haloperidol (5mg dose)	Both quetiapine and haloperidol

Author	Country and setting	Study design	Study aims	Condition of interest	Sample size and population details	Treatment/ intervention	Main findings
			Compare the effectiveness of haloperidol and quetiapine for CD symptoms		(n = 72): Gender: F = 48, M = 25 Age (mean): 31.56 years Quetiapine (n = 71): Gender: F = 42, M = 29 Age (mean): 32.52 years	• Rapid-releasing oral quetiapine (50mg dose)	relieved CD symptoms. It was reported that quetiapine is safer compared to haloperidol due to the prevalence of extrapyramidal side effects being significantly lower in the quetiapine group.
Level 5 evidence							
Bajaj et al., (2017)	India; Setting not reported	Quasi experimental study	Explore effectiveness of CBT in the treatment of FS	FS	N = 50 CBT group (n = 30) Waiting list group (n = 20)	• Weekly comprehensive CBT for 3 months • Waiting control: CAU	The CBT group had a reduction in FS. A statistically-significant difference was found between intervention group and waiting

Author	**Country and setting**	**Study design**	**Study aims**	**Condition of interest**	**Sample size and population details**	**Treatment/ intervention**	**Main findings**
					No other details provided		control in FS frequency.
Baslet et al., (2020)	USA; Hospital	Prospective un-controlled trial	Explore the effectiveness of mindfulness-based therapy (MBT) for FS	FS	N = 49 Therapy completers (n = 26): Gender: F = 23, M = 3 Age (mean): 46.4 years Therapy non-completers (n = 23): Gender: F = 19, M = 4 Age (mean): 34.4 years	MBT	Median FS frequency decreased by 0.12 events/week on average with each completed session ($p = 0.002$). At the last session, 70% reported they had at least a 50% reduction in seizure frequency and 50% reported seizure remission.

Author	Country and setting	Study design	Study aims	Condition of interest	Sample size and population details	Treatment/ intervention	Main findings
Bullock et al., (2015)	USA; Psychiatry department	Prospective naturalistic design	Assess the feasibility of standalone dialectical behaviour therapy skills training (DBT-ST) for CD	CD	N = 19 Gender: F = 18, M = 1 Age (mean): 44.5 years	DBT-ST	The mean seizure rate decreased by 66%. Seizures halted for 35% of participants.
Jain et al., (2020)	India; Hospital	Quasi-experimental study	Study the efficacy of CBT and sertraline to treat CD symptoms	CD	N = 30 Gender: F = 30, M = 0 Age (range): 20-40 years	• CBT and sertraline (50mg) • Sertraline (50mg) alone	CBT and sertraline combined was found to be more effective to improve CD symptoms. Sertraline alone was not found to be effective in reducing CD symptoms.

Author	Country and setting	Study design	Study aims	Condition of interest	Sample size and population details	Treatment/ intervention	Main findings
Petrochilos et al., (2020)	UK; Neuro-psychiatry service	Pre-post study	Provide results from a multidisciplinary team (MDT) treatment programme for FNSD patients	FNSD	N = 100 Included in analysis (n = 78): Gender: F = 60, M = 18 Age (mean): 42.6 years (range: 19-76)	MDT outpatient programme occurred over twice weekly for 5 weeks	An analysis of the time points (baseline, discharge, 6 months) found statistically-significant improvements from both baseline to discharge, and baseline to 6-month follow-up.
Sarudiansky et al., (2020)	Argentina; Epilepsy centre and neuroscience s service	Pre-post longitudinal non-randomised study	Examine the effectiveness of a three-session psycho-educational intervention	FS	N = 12 Gender: F = 10, M = 2 Age (mean): 30.75 years	A three-session group psychoeducation al intervention	Most participants reported a decrease in seizures, and all reported a positive intervention experience.
Aybek et al., (2013)	Switzerland; Neurology	Cohort study	Establish the efficacy of an	CD	N = 23	• Intervention: MDT	Early MDT intervention

Author	Country and setting	Study design	Study aims	Condition of interest	Sample size and population details	Treatment/ intervention	Main findings
	and psychiatry services		early MDT intervention for CD		Intervention group (n = 12): Gender: F = 9, M = 3 Mean age at first symptom = 25.5 years Control group (n = 11): Gender: F = 10, M = 1 Mean age at first symptom = 34.7 years	treatment plan • Control group: CAU	involving neurologists and psychiatrists was found to be effective in the treatment of CD.
Hingray et al., (2018)*	Survey completed across 63 countries	Survey	Examine the diagnosis and treatment of FS globally	FS	N = 1146 (1,098 healthcare workers completed the long survey, 48 completed the short survey)	• Anti-depressant drugs • Psychological therapy	Psychological therapy was the most considered treatment of choice for FS.

Author	Country and setting	Study design	Study aims	Condition of interest	Sample size and population details	Treatment/ intervention	Main findings
					Median age range of respondents: 41-50 years (range: 21-80)		
Jimenez et al., (2019)	USA; Hospital	Retro-spective study	Assess an FND specific interdisciplinary chronic pain rehabilitation program	FND	N = 49 Gender: F = 67.3%, M = 32.7% Age (mean): 42.53 years	Interdisciplinary chronic pain rehabilitation program	Results support the use of interdisciplinary care models for FND treatment.
Kale et al., (2013)	USA; Hospital	Retro-spective chart review	Establish whether adrenergic modulation is an effective FS treatment	FS	N = 14 Gender: F = 11, M = 3 Age (mean): 38.6 years	• Clonidine • Prazosin • Propanolol	Adrenergic modulation of FS associated with PTSD showed a favourable effect in reducing FS.
Maggio et al., (2020)	USA; Physical therapy clinic	Retro-spective cohort study	Establish the efficacy and feasibility of	FND	N = 50 Gender: F = 40, M = 10 Age (mean):	Physical therapy	There was a statistically-significant positive correlation

Author	Country and setting	Study design	Study aims	Condition of interest	Sample size and population details	Treatment/ intervention	Main findings
			physical therapy for FND		46.6 years		between the number of sessions attended and clinical improvement of FND symptoms.
Mayor et al., (2011)	UK; Hospital	Service evaluation	Evaluate brief augmented psychodynamic interpersonal therapy for FS	FS	N = 47 Age (mean): 45 years No other details provided	Psychodynamic interpersonal therapy	25.5% of patients had become seizure-free at follow-up and 40.4% had a seizure reduction of >50%.
Nicholson et al., (2020)	Scotland, USA, and England; N/A	Consensus study	Summarise occupational therapy consensus recommendations for FND assessment and intervention	FND	N = 20 Profession: • Occupational therapist (n = 12) • Neurologist (n = 2)	Occupational therapy	Rehabilitation, education, and self-management strategies were reported to be the most common occupational therapy

Author	Country and setting	Study design	Study aims	Condition of interest	Sample size and population details	Treatment/ intervention	Main findings
					• Neuro-physiotherapist (n = 2) • Patient and public representative (n = 2) • Neuropsychiatrist (n = 1) • Neuro-psychologist (n = 1) No other details provided		interventions for FND.
Tong et al., (2018)*	China; N/A	Survey	Provide an overview of the clinical management of FS in China	FS	N = 102 Gender: F = 62, M = 40. Age: 21–30 = 28 31–40 = 53	• Antidepressant drugs • Anti-epileptic drugs • Antipsychotic drugs	Diagnostic tools and interventions for FS in China are lacking. Hospitals in urban settings were

Author	Country and setting	Study design	Study aims	Condition of interest	Sample size and population details	Treatment/ intervention	Main findings
					41–50 = 15 51–60 = 6	• Benzo-diazepines • Beta-blockers • Education Support groups • Occupational therapy • Psychological treatment	equipped to clinically manage FS, however, more than half of the survey participants stated they would not make the FS diagnosis.

*Record reports more than one research focus so is present in multiple tables.

Table 5: Summary of data charting for the included studies focused on patient and healthcare worker experiences and perspectives

Author	Country and setting	Study design	Study aims	Condition of interest	Sample size and population details	Experience/ perspective type	Main findings
Level 4 evidence							
Fettig et al., (2020)	France; Neurology departments	Longitudinal Ancillary study	Describe the patient-healthcare worker relationship after FS diagnosis and adherence to follow-up appointment	FS	N = 108 Gender: F = 78, M = 30 Mean age: 34 years	Treatment adherence	Between 6-24 months after diagnosis, the number of patients engaged in ongoing care decreased from two-thirds to one-quarter. The most common reasons given for ceasing treatment were spontaneous subjective clinical improvement after diagnosis and lack of interest.
Kanaan et al., (2011)	UK; Setting not reported	Non-randomised survey study	Examine how neurologists understand CD	CD	N = 349 Gender: F = 62, M = 286	Healthcare worker perspectives	Most respondents reported that malingering was

Author	Country and setting	Study design	Study aims	Condition of interest	Sample size and population details	Experience/ perspective type	Main findings
			and how neurologists communicate with patients		Age: <41 = 49 41-45 = 107 46-50 = 81 51-55 = 48 56-60 = 38 >60 = 26		enmeshed with CD, and a minority of respondents saw malingering and CD as similar disorders. Respondents who preferred malingering models were older, whereas younger, female respondents had a preference for psychological models of CD. Younger respondents found communicating with CD patients easier than it was previously.
Monzoni et al., (2011)	UK; Neuroscience centres	Non-randomised study	Describe the resources healthcare	FS and FNSD	N = 20 Gender: F = 12, M = 8	• Healthcare worker perspective	Formulation effort was recognised as the main factor of the challenges

Author	Country and setting	Study design	Study aims	Condition of interest	Sample size and population details	Experience/ perspective type	Main findings
			workers use when delivering a functional symptom diagnosis		Age (mean): 41.5 years (range: 20-75)	- Patient-healthcare worker relationship	faced by healthcare workers during appointments.
Level 5 evidence							
Baxter et al., (2012)	UK; Neurology centre	Interview study	Examine FS patient perceptions of a psycho-educational intervention	FS	N = 12 Gender: F = 8, M = 4 Age (mean): 35.4 years	Patient perspective	To be perceived as useful, psychoeducational treatments for FS should help patients understand psychological causation, and the relationship between the condition and emotions.
Bolton and Goldsmith, (2018)	UK; Setting not reported	Survey	Investigate complaints from FND patients and understand the	FND	N = 58 Profession: Consultant neurologist = 58	- Healthcare worker perspective	The majority of patient complaints were due to disagreement with the FND diagnosis or the

Author	Country and setting	Study design	Study aims	Condition of interest	Sample size and population details	Experience/ perspective type	Main findings
			reaction of consultant neurologists when receiving these complaints		No other details provided	- Patient experience	tools used to make the diagnosis. Patient complaints had a negative effect on the mental wellbeing of many of the participants and also negatively impacted attitudes on work and clinical judgements.
de Schipper et al., (2014)	The Netherlands; the Dutch Society for Neurology and the Department for Consultation-liaison	Survey	Investigate healthcare worker perspectives on the clinical management of FNS	FNS	N = 407 Neurologists (n = 343): Gender: F = 104, M = 239 Age: <41 = 102 41-45 = 41 46-50 = 46	Healthcare worker perspectives	Most respondents reported that disordered brain functioning and psychogenic factors are responsible for FNS. Further, the majority of respondents stated a preference for MDT treatment (explaining the FNS diagnosis,

Author	Country and setting	Study design	Study aims	Condition of interest	Sample size and population details	Experience/ perspective type	Main findings
					51-55 = 59 56-60 = 55 >60 = 40 Psychiatrists (n = 64): Gender: F = 30, M = 34 Age: <41 = 11 41-45 = 4 46-50 = 11 51-55 = 10 56-60 = 17 >60 = 11		physiotherapy and psychotherapy) provided by a trained healthcare worker.
Dworetzky (2015)	USA; Level-4 epilepsy centres	Survey	Examine communication patterns of the FS diagnosis during	FS	N = 126 Profession: Epilepsy expert = 126	Patient-healthcare worker relationship	Only 10% of participants stated that they 'always', and 43% 'occasionally', discuss the possibility of a FS diagnosis to

Author	Country and setting	Study design	Study aims	Condition of interest	Sample size and population details	Experience/ perspective type	Main findings
			practice and training.		No other details provided		patients when applicable. Over 20% of respondents stated on mental health follow-ups were needed, and many respondents 'were not bothered' by patients who challenged the FS and felt they did not need a follow-up appointment. Most respondents provide a maximum of one formal lecture focused on FS when educating trainees.
Fouche et al., (2019)	South Africa; Setting not reported	Interview study	Examine the strategies and barriers experienced	FS	N = 13 Gender: F = 7, M = 6 Practice area:	Healthcare worker perspectives	It was found that a one-size-fits-all approach should not be used when managing FS.

Author	Country and setting	Study design	Study aims	Condition of interest	Sample size and population details	Experience/ perspective type	Main findings
			when communicating the FS diagnosis		• Psychiatry = 5 • Clinical Psychology = 4 • Neurology = 4		
Jones (2020)	UK; Psychology assessment and formulation service	Service evaluation	To explore the views of healthcare workers of the FND psychology pathway	FND	N = 8 Profession: • Physio-therapist = 2 • Clinical specialist physio-therapist = 1 • Consultant physio-therapist = 1 • Epilepsy specialist nurse = 1	Healthcare worker perspectives	Respondents agreed that FND is poorly understood and there is confusion about its terminology. Some respondents had negative opinions about FND and struggled to work with FND patients. Respondents agreed that an MDT approach and an early diagnosis is important.

Author	Country and setting	Study design	Study aims	Condition of interest	Sample size and population details	Experience/ perspective type	Main findings
					• Neurology Consultant = 1 • Occupational therapist = 1 • Rehab Neurology Consultant = 1 No other details were provided		A positive and timely diagnosis is important for patients accepting the FND diagnosis.
Klinke et al., (2019)	Iceland; Rehabilitation centre and acute neurological department	Focus group study	Explore the perspectives of healthcare workers on the facilitators and barriers of inpatient care for FND patients	FND	N = 18 Gender: F = 16, M = 2 Age: 25-29 = 5 30-50 = 6 >50 = 7 Profession: • Nursing = 8	• Facilitators and barriers • Healthcare worker perspective	A trusting relationship between healthcare workers and patients was reported as a major factor for knowing how to help patients to receive treatment. It was reported that FND patients were deemed as a lower priority than

Author	Country and setting	Study design	Study aims	Condition of interest	Sample size and population details	Experience/ perspective type	Main findings
					• Physical therapy = 5 • Medicine = 3 • Occupational therapy = 1 • Neuro-psychology = 1		patients with an organic neurological disorder. Facilitators to clinical management included education, organisational support, documentation of symptoms and professional dialogue. Barriers included stigma, and knowledge and clinical experience of FND.
LaFaver et al., (2020a)	Survey completed in 92 countries	Survey	To determine if opinions on FMD and clinical practices have changed	FMD	N = 864 Gender: F = 286, M = 346 Age:	Healthcare worker perspective	The clinical management of FMD varied widely. Many neurologists used exclusionary diagnosis techniques instead of ‘positive’ diagnostic

Author	Country and setting	Study design	Study aims	Condition of interest	Sample size and population details	Experience/ perspective type	Main findings
					25-35 = 189 36-45 = 220 46-55 = 115 56-65 = 85 >66 = 25		criteria. Differences in FMD clinical management were somewhat explained by practices between countries but not by age, gender or years in practice.
Lehn et al., (2019)	Australia; N/A	Survey	Identify support needs and knowledge gaps of health professions in contact with FND patients	FND	N = 516 Gender: F = 74.3%, M = 25.7% Age (mean): 43.4 years Profession: • Physio-therapist = 195 • Psychologist	Healthcare worker perspective	Neurologists, nurses, and GP respondents were more likely to report having a negative attitude towards FND. While FND patients are seen by many healthcare workers, little FND training was provided. Most respondents did not feel sufficiently trained about

Author	**Country and setting**	**Study design**	**Study aims**	**Condition of interest**	**Sample size and population details**	**Experience/ perspective type**	**Main findings**
					= 81 - Neurologist = 79 - Neuroscience nurse = 70 - General practitioners = 56 - Psychiatrist = 35		FND; only 14% of GPs reported having 'good' FND knowledge. Most respondents did not feel confident discussing an FND diagnosis with patients. Seeing more FND patients was significantly correlated with having confidence diagnosing the condition (r = 0.49) and confidence in communicating the FND diagnosis (r = 0.44).
O'Connell (2017)	N/A	PhD study	Assess the experiences of patients and healthcare	FND	N = 152 Healthcare workers	- Healthcare worker perspective	Healthcare workers' lack of awareness of FND may worsen patients' symptoms and

Author	Country and setting	Study design	Study aims	Condition of interest	Sample size and population details	Experience/ perspective type	Main findings
			workers on treatment interventions for FND		(n = 122): Gender: F = 87, M = 29, missing = 6 Age (mean): 34.5 years Patients (n = 30): Gender: F = 22, M = 8 Age (mean): 48.9 years	- Patient perspective	experiences in health care.
Perez et al., (2016)	USA; FND clinic	Retro-spective case review	Investigate predictors of initial attendance of suspected FNSD patients referred to FND clinics	FNSD	N = 62 Gender: F = 46, M = 16 Age (mean): 37.8 years	Facilitators and barriers to treatment adherence	FNSD patients referred from the accident and emergency department were less likely to attend the first appointment than patients referred from other services.

Author	Country and setting	Study design	Study aims	Condition of interest	Sample size and population details	Experience/ perspective type	Main findings
Pretorius and Sparrow, (2015)	South Africa; Epilepsy Unit and neurology department	Interview study	Examine the life experiences patients with FS	FS	N = 10 Gender: F = 8, M = 2 Age (mean): 39.2 years (range: 19-55)	Patient experience	Patients diagnosed with FS experienced both challenges and resources. Experiences of resources included religion and spirituality, social support, and healthcare workers. Challenges experienced included healthcare workers, belief systems, family, and unexpected seizures. As healthcare workers were described as both a resource and a challenge, it can be assumed that they are key in the experiences

Author	Country and setting	Study design	Study aims	Condition of interest	Sample size and population details	Experience/ perspective type	Main findings
							of patients diagnosed with FS.
Pretorius (2016)	South Africa; Hospital	Interview study	Examine the experiences of FS patients during the diagnostic process	FS	N = 10 Gender: F = 8, M = 2 Age (mean): 39.2 years (range: 26-55)	Patient perspective	Analysis revealed that an early FS diagnosis is vital to not only address the patient’s loss of independence, but also to reduce healthcare burden and the chance of potentially harmful interventions. It was found that FS education courses for healthcare workers can lead to patients having a positive FS diagnostic experience.
Rawlings et al., (2017)	UK; Setting not reported	Qualitative writing study	Explore patient experiences of living with FS	FS	N = 19 Gender: F = 16, M = 3	Patient perspective	It was found that patients perceived FS as having an

Author	Country and setting	Study design	Study aims	Condition of interest	Sample size and population details	Experience/ perspective type	Main findings
					Age (mean): 42 years		incapacitating effect. There was a lack of understanding of the condition by healthcare workers, the public and patients. Further, patients struggled with their mental health and self-worth, and most had experienced a past traumatic event. Seizure symptoms, treatments, and outcomes were reported by participants.
Read et al., (2020)	UK; Setting not reported	Interview study	Explore participants' experience of CBT	FS	N = 30 Gender: F = 21, M = 9 Age range: 18-80	Patient perspective	Patients who received CBT reported that the techniques learnt during CBT treatment were simple to practice and gave them better control

Author	Country and setting	Study design	Study aims	Condition of interest	Sample size and population details	Experience/ perspective type	Main findings
							over their seizures. A positive therapeutic alliance led to patients being more connected to their emotions.
Sahaya et al., (2012)	USA; Hospital	Survey	Explore the opinion of healthcare workers on FS	FS	N = 115 Profession: • Primary care doctors = 60 • Nurses = 39 • Neurologists = 16	Healthcare worker perspective	Both nurses and neurologists reported a high level of confidence in the clinical management of FS. Although 61% of respondents stated that FS were involuntary, 48% of nurses surveyed stated that patients have voluntary control over their non-epileptic seizures and that FS is fake.

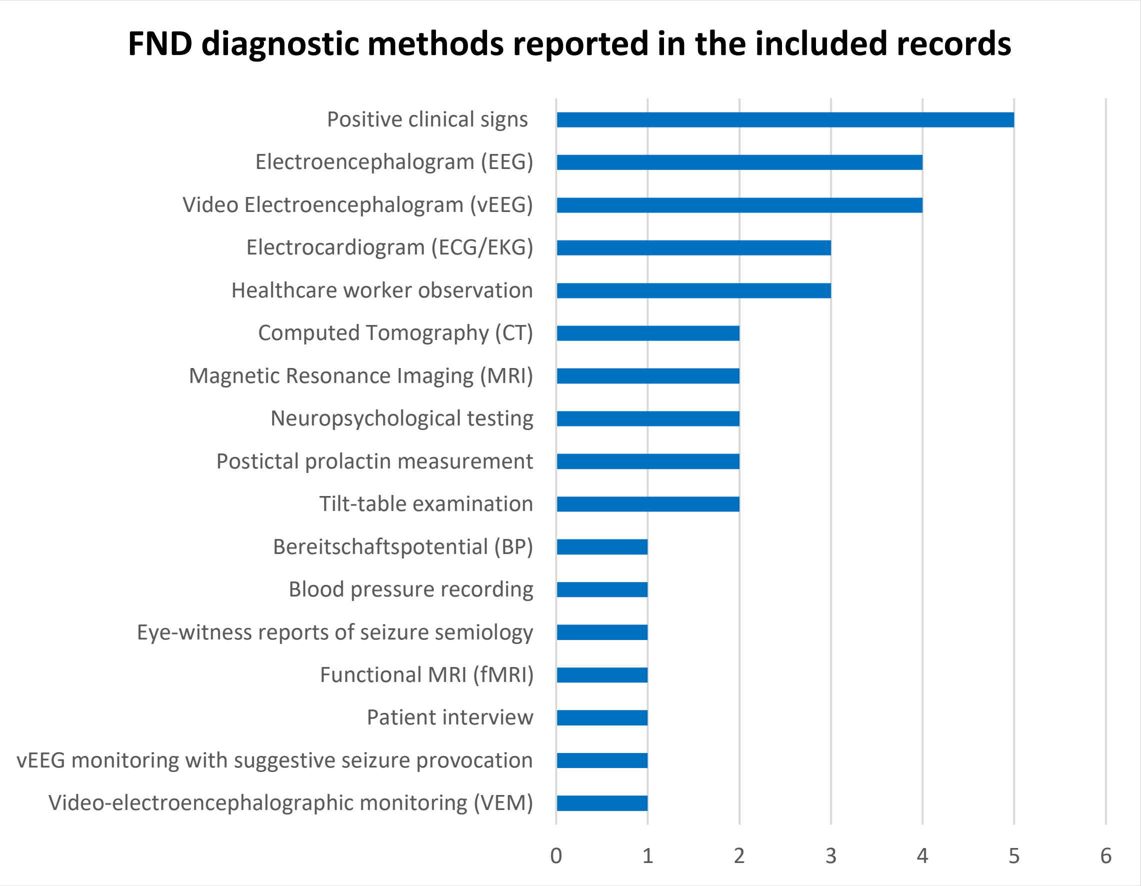
Author	Country and setting	Study design	Study aims	Condition of interest	Sample size and population details	Experience/ perspective type	Main findings
Tolchin et al., (2018)	USA; Hospital	Prospective cohort study	Investigate long-term adherence to psychiatric treatment	FS	N = 123 Gender: F = 104, M = 19 Age (mean): 38 years (range: 18-80)	Treatment adherence	80% of participants attended the first outpatient appointment, whereas only 14% attended all four outpatient appointments. Prior diagnosis of FS (hazard ratio: 1.57, p = .046) and a low score on the Brief Illness Perception Questionnaire (hazard ratio: 0.77 for every 10-point increment, p = .008) were linked to low adherence.
Wyatt et al., (2014)	UK;	Qualitative interviews	Explore patient experiences of	FS	N = 6 Gender: F = 5, M = 1	• Patient experience	The attitude of the healthcare worker had

Author	Country and setting	Study design	Study aims	Condition of interest	Sample size and population details	Experience/ perspective type	Main findings
	Adult neuro-psychology NHS service		psychological therapy		Age (mean): 47.3 years (range: 20-55)	• Treatment adherence	an impact on treatment engagement.

2.5.2 Diagnostic methods

Figure 3 (below) represents the diagnostic methods reported in the included studies.

Figure 3: Diagnostic methods reported in included studies



Until recently, an FND diagnosis consisted of diagnosing by ‘exclusion’, where tests for other conditions were conducted and organic conditions ruled out, to ensure that the FND diagnosis was viable (LaFaver et al., 2020a). However, recent procedures now focus on identifying positive clinical signs. This is clear by the types of diagnostic methods predominantly reported in the included records: positive clinical signs, video electroencephalogram (vEEG), electroencephalogram (EEG), and electrocardiogram (ECG/EKG).

2.5.2.1 Positive clinical signs

Positive clinical signs (such as Hoover’s sign, or drift without pronation sign) were reported in five of the included studies. McWhirter and colleagues (2011) high quality, prospective cohort study (n = 337) investigated Hoover’s sign as one element of the functional weakness diagnostic work-up. The study found that the sign was a very specific (100%; 95% CI: 97 to 100) and moderately sensitive (63%; 95% CI: 24 to 91) test for an

FND diagnosis in patients with unilateral leg weakness. A further study investigated the drift without pronation positive sign and observed it in 100% of FND participants but in only 7.1% of organic patients (100% sensitivity and 93% specificity; Daum and Aybek, 2013). The ‘huffing and puffing’ sign was also examined and found to be highly specific (91%; 95% CI: 76 to 98) but yielded low sensitivity (57%; 95% CI: 48 to 66) for an FMD diagnosis (Laub et al., 2015). Lastly, Daum and colleagues’ pilot study (2015) investigated the validity of using positive signs for functional neurological disorder by measuring the interobserver agreement of two blinded neurologists who were tasked with rating the video recordings of 20 standardised neurological tests. The study determined that six positive signs could be classified as ‘highly reliable signs’ and had good to excellent inter-rater reliability. These signs included: Giveway weakness (100% specificity and 85% sensitivity), Drift without pronation (95% specificity and 61% sensitivity), Co-contraction (100% specificity and 30% sensitivity), Splitting the midline (100% specificity and 42% sensitivity), Splitting of vibration sense (88% specificity and 50% sensitivity) and Hoover’s sign (100% specificity and 76% sensitivity).

2.5.2.2 Neurological examinations

Several neurological tests were reported, with vEEG and EEG being the most studied (n = 8). Several studies found that vEEG and EEG assessments were able to discriminate between FS and epilepsy (Syed et al., 2011, Varone et al., 2020). One study found that vEEG plus suggestive seizure provocation significantly contributed to an accurate FS diagnosis (Nežádal et al., 2011). Wegrzyk and colleagues (2018) prospective study (n = 48) investigated whether resting-state fMRI could discriminate FND patients from control participants. The study reported positive results when using fRMI to diagnose FND, with specificity, sensitivity and accuracy over 68% (p = 0.004) when discriminating between the FND group and control group. Video-electroencephalographic monitoring (VEM) was reported in one retrospective case review (Foong and Seneviratne, 2016). Foong and Seneviratne (2016) aimed to determine the ideal duration to capture VEM and found that monitoring for five days yielded the greatest number of diagnostic seizures. Indeed, the study reported that this duration and technique may be sufficient to diagnose up to 99% of FS patients.

2.5.2.3 Eyewitness reports, observations and interviews

Eyewitness reports, patient interviews and healthcare worker observations were reported in the included records. Biberon and colleagues (2020) blinded prospective study (n = 32) evaluated conversational analysis (via patient interviews) to differentiate between FS from epilepsy. Using blinded assessments, it was found the reviewers had a high correct prediction rate (84% and 88%) when differentiating FS from epilepsy, indicating that conversational analysis can be a useful and reliable tool to diagnose FS. In a similar fashion, MacDonald and colleagues (2012) determined the accuracy of healthcare worker observations to differentiate FS from epilepsy using videotaped events. However, only 55.4% of correct diagnoses were made and neither the psychiatric nor general medical workers were confident in reaching a diagnosis. The use of an automated and ambulatory device to detect FS was examined by Naganur and colleagues (2019). The wrist-worn device was used to collect accelerometer information from patients and compared to VEM; it was found that the device detected all seizures and had a sensitivity of 72.7% and specificity of 100% in classifying epileptic seizures from FS. Finally, Syed and colleagues (2011) assessed eye-witness reports of seizure semiology during vEEG and identified signs that could discriminate between FS and epilepsy during vEEG assessments. However, it was reported that unreliable eyewitness accounts of semiology hindered the prediction of FS.

2.5.2.4 Surveys

Three included records utilised survey methods to examine the diagnostic tools used by healthcare workers (Asadi-Pooya, 2016, Hingray et al., 2018, Tong et al., 2018). One study found that there is a large variability in the tools used to diagnose functional disorders (Asadi-Pooya, 2016). All three surveys reported the use of neurological tests (vEEG, EEG, MRI and CT scans) to assist in the diagnosis of FND. However, a clear relationship between the country’s income or geographic location (e.g., urban setting or rural) and access to diagnostic tools were found, with healthcare workers based in urban settings and/or high-income countries having better access (Hingray et al., 2018, Tong et al., 2018).

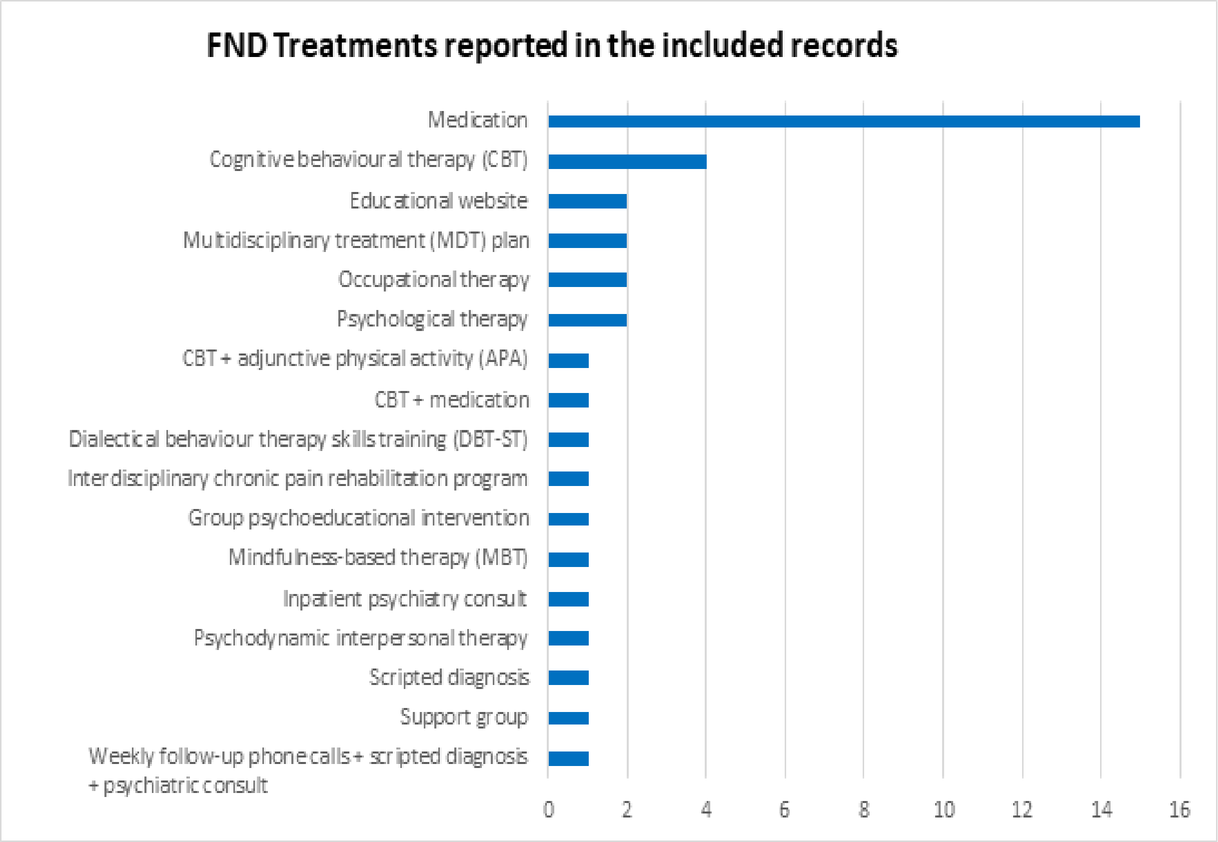
2.5.2.5 Misdiagnosis

Misdiagnosis (also known as diagnostic error) is the incorrect diagnosis of a condition or disease (Balogh et al., 2015). One study (van der Feltz-Cornelis et al., 2020) researched how FND predictors (such as stressful life events or childhood adverse experiences) can be used as a misdiagnosis indicator. The study found that there are no clinical factors which predict an FND misdiagnosis and that 12% of the patients included in the study were misdiagnosed. The study recommended re-evaluating the diagnosis of chronic FND patients to ensure they had not been misdiagnosed. Walzl and colleagues (2019) examined how functional disorders were misdiagnosed as a neurological disorder and found that 2% (n = 48) of patients who were able to be followed-up (n = 2,378) were misdiagnosed. There is a big difference in diagnosis rates between the Walzl and colleagues’ (2019) and van der Feltz-Cornelis and colleagues’ (2020) findings, perhaps due to differences in sample sizes or geographical location.

2.5.3 Treatments/interventions

Figure 4 represents the treatments reported in the included studies.

Figure 4: Treatments reported in included studies



2.5.3.1 Psychological therapies

Cognitive behavioural therapy (CBT), mindfulness-based therapy, dialectical behavioural therapy (DBT) and psychodynamic therapy were the most common psychological interventions reported in the included studies. CBT was the most studied psychological intervention. A pilot RCT found that CBT was effective in improving functional movement disorder (FMD) symptoms. These findings are supported by Espay and colleagues' (2019) pilot study (n = 15) which investigated the effectiveness of CBT on functional tremor, and found that the therapy improved tremor severity and 73.3% of participants had a near or full remission. A pilot randomised controlled trial (n = 29) assessing the feasibility and efficacy of CBT plus adjunctive physical activity (APA) found that CBT was effective in improving functional symptoms, whereas no favourable effect from APA alone was found (Dallocchio et al., 2016).While a recent large RCT (n = 368) comparing the effectiveness of CBT plus standard medical care, versus care as usual, for FS reported that no statistically significant difference was found between the groups at 12 months, improvements were seen in psychosocial functioning and perceptions of health (Goldstein et al., 2020).

In Baslet and colleagues' (2020) study exploring the effectiveness of mindfulness-based therapy for FS, median FS frequency decreased with each successive session. During the last session, 70% of participants reported they had at least a 50% reduction in seizure frequency, whilst 50% reported seizure remission. Similarly, it was found that DBT skills training led to a mean seizure rate decrease by 66%, and seizures stopped for 35% of the participants (Bullock et al., 2015).

Two records reported on the effectiveness of psychodynamic therapy for functional disorders. Hubschmid and colleagues (2015) RCT (n = 23) compared a brief psychotherapeutic intervention based on a psychodynamic interpersonal treatment to care as usual and found a statistically significant improvement of psychological and physical symptoms, along with a reduction in new hospital stays in the intervention group ($p = <0.05$). Supporting these findings, a service evaluation aiming to establish the outcome of brief augmented psychodynamic interpersonal therapy found that 25.5% of FS patients had become seizure-free at follow-up and 40.4% had a seizure reduction of more than 50% (Mayor et al., 2011).

2.5.3.2 Medication

Prescribed medication (such as antidepressants, anti-epileptics and benzodiazepines) was investigated in 15 studies. Jafari and colleagues'(2018) RCT (n = 140) compared the effect of midazolam versus haloperidol on FND symptoms and found that haloperidol was significantly more effective in managing FND symptoms than midazolam. However, haloperidol was associated with more side-effects than midazolam. Another RCT (n = 144) investigating haloperidol and quetiapine reported that both medications were similar in their effectiveness in reducing FND symptoms. However, fewer side effects were reported in the quetiapine group than in the haloperidol group (Ghanbarizadeh et al., 2018). Kale and colleagues (2013) found that adrenergic modulation therapy was beneficial in reducing FS. However, in studies comparing medication to psychological treatment, the psychological treatment arms were found to be more effective in reducing FND symptoms than medication (Bajaj et al., 2017, Jain et al., 2020).

2.5.3.3 Psychoeducational interventions

Two studies reported the effectiveness of psychoeducational interventions for functional disorders. Sarundiansky and colleagues (2020) conducted a non-randomised study to examine the effectiveness of a three-session psychoeducational intervention. The majority of participants reported a decrease in seizure frequency, and all reported that the intervention was a positive experience. Cope and colleagues (2017a) pilot study (n = 19), which aimed to test the effectiveness of a CBT-based psycho-education group on reducing FS frequency, supports these findings, reporting that the group was beneficial , with almost 40% of treatment completers being seizure free.

2.5.3.4 Multidisciplinary treatment plans

Multidisciplinary treatment plans were also investigated. Aybek and colleagues (2013) conducted a cohort study exploring the effectiveness of an early multidisciplinary intervention involving neurologists and psychiatrists, and found that utilising a multidisciplinary treatment plan was effective in the treatment of FND symptoms. These findings are supported by Petrochilos and colleagues' (2020) study, who reported a statistically significant improvement in participants involved in an MDT outpatient programme, from both baseline to discharge and baseline to 6-month follow-up. A retrospective study (assessing an interdisciplinary chronic pain rehabilitation programme) found that FND patients using the programme had a reduction in pain-related disability, depression, anxiety and stress.

2.5.3.5 Other treatment options

The remaining studies reported on occupational therapy, physical therapy, educational websites, scripted diagnosis, weekly follow up phone calls and inpatient psychiatry consultations. Maggio and colleagues (2020) explored the feasibility and efficacy of physical therapy for FND symptoms, and found a statistically significant positive correlation between the number of sessions attended and clinical improvement. A consensus study led by Nicholson and colleagues (2020) found that the main occupational therapy interventions for FND included rehabilitation, education and self-management strategies. Gelauff and colleagues (2020) conducted an RCT (n = 186) to establish the effectiveness of utilising an education/self-help website plus care as usual compared to usual care only, finding that the online education/ self-help website was not an effective treatment (p = 0.899). Finally, an RCT (n = 30) evaluating the common clinical management methods for FS (scripted diagnosis, inpatient psychiatry consult, weekly follow-up phone calls) found that the participants in the scripted diagnosis and psychiatric consultation group had a reduction in seizures, whereas participants receiving weekly phone calls had a reduction in seizures and improved mood (Drane et al., 2016).

2.5.4 Experiences and perspectives

The experiences and perspectives of healthcare workers, patients and caregivers on the diagnosis and treatment of FND were reported in multiple studies.

2.5.4.1 Healthcare worker perspectives

Healthcare worker perspectives were typically collected via survey (Kanaan et al., 2011, Lehn et al., 2019, Sahaya et al., 2012). One study found that healthcare workers reported they were confident in the clinical management of FS patients (Sahaya et al., 2012), whereas another found that most respondents did not feel confident discussing the diagnosis with patients (Lehn et al., 2019). Seeing more FND patients was significantly correlated with having confidence in diagnosing the condition (r = 0.49) and confidence in discussing the FND diagnosis with the patient (r = 0.44; Lehn et al., 2019).

Malingering and negativity towards FND was explored in two surveys, finding that 48% of nurses believed patients have voluntary control over their non-epileptic seizures and that FS is not a real condition (Sahaya et al., 2012), and that neurologists, nurses and GP respondents were more likely to report having a negative attitude towards FND (Lehn et al., 2019). Further to this, a minority of the respondents in the Kanaan and colleagues (2011) study stated that malingering and FND are similar disorders. This finding is contradicted in the de Schipper and colleagues (2014) survey, who found that most respondents believed that disordered brain functioning and psychogenic factors are responsible for FND onset.

Healthcare worker opinions and perspectives on the clinical management of functional disorders were explored in several studies. Fouche and colleagues (2019) reported that healthcare workers agreed a one-size-fits-all approach should not be used when managing functional seizures. In another study (Jones, 2020), participants reported that using an MDT approach to the clinical management of FND is important.

2.5.4.2 Patient perspectives

Patient perspectives and experiences were also reported in the included records. The perceptions of the clinical management of FND differed greatly between patients (Rawlings et al., 2017). Patient perspectives on FND treatments were explored by Baxter and colleagues (2012), finding that treatments which help patients both understand the onset of the condition, as well as the relationship between it and emotions, were perceived as useful.

Rawlings and colleagues’ (2017) study explored the challenges and resources experienced by patients, and found that spirituality, religion and support were resources, whereas belief systems, family and unexpected seizures were seen as challenges. Patients in multiple studies reported how healthcare workers were key in the experiences of patients diagnosed with functional seizures (O'Connell, 2017, Pretorius, 2016, Pretorius and Sparrow, 2015). These findings relate to a further study (Dworetzky, 2015) exploring the patient-healthcare worker relationship, where only 10% of healthcare worker participants stated that they “always” discussed the possibility of a functional seizure diagnosis to patients when applicable, and 43% stated they “occasionally” discussed the condition with patients. In addition, many participants ‘were not bothered’ by patients who challenged the FS diagnosis and felt they did not need a follow-up appointment. Bolton and Goldsmith’s (2018) research surveyed healthcare workers on FND patient complaints, and aimed to understand the reaction of consultant neurologists when receiving said complaints. The majority of complaints were due to disagreements with the FND diagnosis or the tools used to make the diagnosis. In addition, patient complaints had a negative impact on the mental well-being of many of the surveyed healthcare workers; it also negatively impacted attitudes on work and clinical judgements.

2.5.4.3 Facilitators and barriers

Several facilitators and barriers to the clinical management of functional disorders were noted in the included records. Facilitators included the attitude of the healthcare worker involved in both diagnosis and treatment processes (Wyatt et al., 2014) and organisational support (Klinke et al., 2019), whereas barriers included a lack of interest or need for care (Fettig et al., 2020), stigma and limited knowledge of FND (Klinke et al., 2019), and referrals to services from the accident and emergency department (Perez et al., 2016).

The experiences and perspectives of healthcare workers, patients and caregivers are further explored in the thematic analysis (reported in Section 2.6).

2.5.5 Clinical guidelines

One of the objectives of this review was to identify and compare international FND guidelines. It was originally planned that the international guidelines would be compared to UK guidance, but as stated previously, there is currently no official National Institute for Health and Care Excellence (NICE) guidance for FND.

Only three clinical guidelines were retrieved from the searches, all from European countries (Denmark, Germany, and The Netherlands). Two were published (or updated) within the last four years (Germany and The Netherlands), whereas the Danish guidelines were published in 2013. The three guidelines are summarised and compared below.

The Danish guidance (Danish College of General Practitioners, 2013) is aimed at general practitioners, but can also be used by other healthcare workers. It recommends following the ICD-10 criteria (World Health Organization, 2004), and that the condition should not be better explained by organic disorder, abuse, psychosis, affective conditions or any anxiety condition. However, the guidance recognises that it is difficult to follow the ICD-10 criteria in general practice, and that there is no commonly accepted or validated test for these patients in a general practice setting. To make a diagnosis, a comprehensive assessment should be completed and include taking the patient’s medical history and completing the Common Mental Disorders Questionnaire (CMDQ; Christensen et al., 2005) alongside a physical examination combined with blood tests. The diagnostic tests should be excluded via history taking, and healthcare workers should consider screening for mental disorders.

The Danish guidance (Danish College of General Practitioners, 2013) also recommends that the biopsychosocial model is followed for treatment, and a stepped care approach with a focus on multidisciplinary care should be utilised. Before starting treatment, the healthcare worker should determine which level (in the stepped care approach) is most suitable for the patient. Mild functional symptoms are typically treated in general practice whereas severe symptoms involve multidisciplinary treatment, including CBT and physiotherapy. Patients with severe symptoms may benefit from pharmacological treatment (such as antidepressants or anticonvulsants), but prescribing addictive medication should be avoided. This guidance is unique in that it provides information on how to clinically manage FND experienced by elderly patients and recognises how most studies only included patients aged under 65 years, so the available evidence is very limited. It recommends that treatments for elderly patients should focus on psychological therapy, mental support and pharmacological treatments (such as acetaminophen). However, medication containing morphine or those with anticholinergic effects should be avoided.

The guideline developed in the Netherlands was recently updated (GGZ Standaarden, 2021); it recommends that diagnosis and severity of symptoms should be determined through somatic and psychological diagnostics. Contrasting the Danish and German guidelines, the Dutch guidelines state that the DSM-5 (American Psychiatric Association, 2013) criteria should be followed, and an assessment should be performed for each clinical presentation. Somatic and psychological diagnostics should take place, with staging and profiling of the potential disorder being investigated. Additional diagnostics may be necessary to rule-out a structural disorder, typically consisting of imaging and neurophysiological examination.

In comparison to the Danish guidelines, the Dutch guideline recommended treatment follows the biopsychosocial model, with emphasis placed on establishing a trusting relationship between healthcare worker and the patient, which encourages shared decision-making. Integrated multi- or inter-disciplinary treatment should be offered to all patients, however monodisciplinary care may be offered, depending on the patient's symptoms and severity. Recommended treatments include psychological therapy (such as psychodynamic psychotherapy or CBT), psychoeducation for both the patient and their relatives/caregivers, hypnotherapy, physiotherapy, eye movement desensitisation and reprocessing (EMDR), and virtual reality. Pharmacological treatment is not recommended, and there are no specific self-management interventions available.

The German guidance (Roenneberg et al., 2019), similar to the Dutch guideline, recommends that diagnosis and severity of symptoms should be determined through somatic and psychological diagnostics. Patient history should be taken (which includes an assessment of psychological state) alongside a physical examination. Once the initial examinations have taken place, additional diagnostic investigations may be performed but only after careful consideration. If no diagnosis can be determined via these investigations, the guidance recommends that healthcare workers use the ICD-10 symptom codes (World Health Organization, 2004).

Treatment should follow a severity-staged, collaborative and coordinated three step model of care. Similar to the Danish and Dutch guidelines, the German guidance (Roenneberg et al., 2019) states that the biopsychosocial model should be followed, and should consider the patient's individual risk factors, as well as any relevant context factors. An integrative approach to treatment is recommended, with basic care (such as encouraging the patient to lead a physically active lifestyle) being offered by the patient's primary care doctor. Multimodal treatments should be considered, such as psychotherapy, medications (including psychopharmaceuticals), psychoeducation, relaxation techniques and passive complementary medicine (such as phytotherapy and acupuncture).

Each guideline emphasises the importance of the patient-healthcare worker relationship and recognises how healthcare workers involved in the patient's care should acknowledge the patient's symptoms and thoughts. The Dutch guideline (GGZ Standaarden, 2021) iterates how patients must be taken seriously, and that healthcare workers must have a respectful and open approach when working with patients. In addition, the Dutch guideline highlights the need to provide a good and clear diagnostic explanation to patients, as it encourages the patient's acceptance of the diagnosis. This is supported by both the German and Danish guidelines, which state that careful and attentive listening (and also conscious proactive behaviour) not only strengthens the patient-healthcare worker relationship, but also reduces potential iatrogenic harm.

Although not of focus in this review, the Danish and Dutch guidelines (Danish College of General Practitioners, 2013, GGZ Standaarden, 2021) provide guidance on the clinical management of children and adolescents. FND diagnostic assessments for children and adolescents are similar to adult patients, however a parent or guardian is required to provide details of the patient's medical history and symptoms. In addition, an evaluation of the child and parent/guardian interacting with one another is often performed, alongside retrieving information from the child's school if needed. There are currently no evidence-based treatments specifically for children and adolescents with a functional disorder (Danish College of General Practitioners, 2013), however a stepped care approach is recommended which includes supporting the child and their family/guardians and providing pharmacological treatment.

2.6 Thematic analysis

A thematic analysis was conducted using the relevant literature retrieved from the searches. Data was coded using NVivo V.12 and grouped into four themes:

- Attitudes towards FND
- Communication
- Barriers and facilitators to care
- Acceptance of FND

2.6.1 Attitudes towards FND

Patient, healthcare worker and caregiver attitudes were mainly explored in interview and survey studies. Most data relating to this theme reported negative attitudes, especially those belonging to healthcare workers about the condition and FND patients.

2.6.1.1 Stigma

Fouche and colleagues (2019) reported that patients with FND were not only frequently dismissed by healthcare workers, but also faced stigma by their own community and the medical community (including psychiatrists and neurologists). Stigma and negative attitudes from healthcare workers may be connected to a lack of education or understanding of the condition (Plioplys et al., 2017). Other studies found that stigma appeared in both tangible and less tangible ways. For example, experienced healthcare workers reported being annoyed due to the amount of time patients with FND required during the clinical management of the condition:

> *"…I sometimes become really annoyed. Recently, a patient had a functional seizure exactly at the same time as I received a critically ill patient from the*

> *intensive care unit. At that moment I just thought “For God’s sake – stop seizing” ... and then I felt bad about that later on.”* (Klinke et al., 2019, p.7)

In addition, FND was not listed as a condition treated in the specific neurology service included in Klinke and colleagues’ (2019) study, yet the frequency of FND patients attending the ward was comparable to other neurological conditions. Indeed, FND is the second most common reason to attend a neurology service (Stone et al., 2010). These negative attitudes can in turn impact on patients’, with patients less likely to accept the FND diagnosis and engage with therapy (Fouche et al., 2019, Plioplys et al., 2017). Fouche and colleagues (2019) found that healthcare workers gaining confidence in approaching FND patients (and acquiring more knowledge) led to a reduction in stigma.

2.6.1.2 Healthcare worker attitudes and feelings of frustration

There are mixed findings on the attitudes of healthcare workers about FND. Although recent studies found that more healthcare workers report a positive attitude and willingness to treat the condition, attitude is dependent on clinical specialty (Plioplys et al., 2017). Primary care and emergency healthcare workers are less likely to accept FS as a valid diagnosis; in one survey, psychiatrists and neurologists believed that FS patients had greater control over their seizures than epilepsy patients. These findings are supported by other studies, which reported that 48% of nurse respondents believed that FS patients were malingering and in control over their seizures, and also how stroke healthcare workers do not believe FS patients have an undiagnosed physical illness (Sahaya et al., 2012, O'Connell, 2017). This may be due to the limited validated diagnostic methods available, or a lack of FND-specific education for healthcare workers.

Frustration is a common emotion reported in healthcare worker surveys focused on the management of FND. One study reported that 72% of respondents perceived patients (with unexplained symptoms) causing them considerable stress. It was speculated that this stress and frustration may have been felt by healthcare workers due to being unable to help patients, and not being able to diagnose chronic patients showing the same symptoms (Plioplys et al., 2017).

Several studies have explored how negative attitudes towards FND could be ameliorated (McWhirter et al., 2011, Monzoni et al., 2011). The main facilitator in changing negative attitudes was proactive education, as a lack of understanding about the condition was found to be a significant challenge for healthcare workers who did not work frequently with FND patients (McWhirter et al., 2011, Monzoni et al., 2011). In addition, engaging with patients and discussing findings with other healthcare workers led to a change in attitude (Monzoni et al., 2011). Reflection was found to be one strategy in coping with frustration and negative attitudes; it can help healthcare workers recognise any potential anxieties or disbeliefs of the condition and can be facilitated via mentorship and discussions (Plioplys et al., 2017).

2.6.1.3 The effect of negative attitudes on patients

It is apparent that the attitudes of healthcare workers and the community can have a negative effect on FND patients and their outcomes. FND patients in one study reported that they were aware of the suspicion their diagnosis faced from healthcare workers and were sensitive to the negative attitudes expressed by clinical teams (McWhirter et al., 2011). This finding is supported by Mayor and colleagues (2011), who found that FND patients were aware of the negative views expressed by healthcare workers.

It has been reported that negative attitudes may affect how healthcare workers interact and present diagnoses to patients, this in turn impacts on how the patient perceives their diagnosis. Participants in McWhirter and colleagues' (2011) study reported that they felt there was a lack of interest in their condition, and that they were not listened to or supported by healthcare workers (specifically paramedics and emergency department healthcare workers). These negative attitudes can lead to patients not trusting healthcare workers, becoming angry (Plioplys et al., 2017) and not engaging with treatments (Rawlings et al., 2017).

2.6.2 Communication

Communication is a key issue in many of the included studies. Several studies have explored the differences between healthcare workers (when communicating with patients), the patient-healthcare worker relationship, and healthcare worker communication skills.

2.6.2.1 Communication differences

Healthcare worker communication styles differ when communicating between departments and with patients. Several determinants of communication have been reported, with gender, age, and knowledge being key. Kanaan and colleagues' (2011) study found that female healthcare workers were more likely to communicate the FND diagnosis to patients on the same day it was determined, and also communicate better with a receptive patient than their male counterparts. In addition, female healthcare workers were much more likely to discuss psychological factors with patients. Younger healthcare workers were found to be more communicative with patients than their older counterparts, with many believing it is easier to communicate a diagnosis in present time than it was in the past (Kanaan et al., 2011).

The income status of a country is a further indicator of communication differences. In high income countries, 94% of neurologists were found to provide the FND diagnosis, versus 66% of psychiatrists. In low-income countries, these figures drop dramatically to 33% and 5%, respectively (Hingray et al., 2018). Healthcare workers in high income countries were also more likely to discuss aetiological explanations of FND than healthcare workers in low-income countries (Hingray et al., 2018).

Differences in communicating the FND diagnosis to patients have also been reported. Some studies have reported that only one healthcare worker should be involved in reporting the diagnosis, whereas others have suggested a team approach should be utilised. McWhirter and colleagues' (2011) reported that the healthcare worker who has the strongest patient-healthcare worker relationship (or who made the diagnosis) should be the person communicating with the patient, stating that this is especially pertinent when the patient has had negative experiences with previous healthcare workers when attempting to navigate the diagnostic pathway. In contrast, Kanaan and colleagues' (2011) found that a whole-team approach should be applied when communicating the diagnosis, as it provides unity with all those involved.

2.6.2.2 Communication difficulties and lack of communication

Communicating the FND diagnosis has been typically seen as difficult by both healthcare workers and patients. Patients have previously reported being unable to talk to healthcare workers and were not understood when attempting to give a meaning to their illness (Cottencin, 2014). Other studies have found that patients may not comprehend the information given to them during the diagnosis meeting (Fobian and Elliott, 2019), indicating they may need the diagnostic information communicated to them in a less stressful, emotionally charged setting.

Communication difficulties between clinical departments may lead to issues in patient care. Monzoni and colleagues (2011) reported how interdisciplinary communication can negatively impact patient care, due to a difficulty in knowing which healthcare worker was responsible for the care, preventing a streamlined approach being put in place. However, these negative impacts can be reduced by implementing regular team meetings and care coordination (Monzoni et al., 2011).

How the diagnosis is communicated can impact how the patient perceives and accepts the information. Not providing a diagnosis (or only sharing the diagnosis) may lead to a negative prognosis, or even the patient developing more FND symptoms (Espay et al., 2018, LaFaver et al., 2020a). Language barriers have also been reported as a further communication difficulty. For example, not providing a translator or interpreter when there is a language barrier can cause difficulties for the patient when trying to understand the diagnosis (McWhirter et al., 2011). Communicating the diagnosis using a tactful, empathetic and informative approach using simple terms can lead to more favourable outcomes (Sahaya et al., 2011). In addition, enough time should be allotted for the diagnostic appointment to ensure the patient's feelings and complaints can be heard and discussed (Stone, 2016).

Lastly, clinical services have also experienced communication difficulties. It has been reported that information relating to a patient's diagnostic process has not been disseminated between teams, leading to healthcare workers not feeling confident when communicating with patients. Communication difficulties have also arisen in interdisciplinary communication when responding and documenting observations (Monzoni et al., 2011).

2.6.2.3 Patient-healthcare worker relationship

When communicating with the patient during the diagnostic appointment, the meeting can be a very fragile yet opportunistic moment. The appointment can be used to encourage a patient to understand the condition and accept the diagnosis. Developing a trusting patient-healthcare worker relationship is vital to support patients, and the patient-healthcare worker relationship is reliant on effective communication between both parties. Plioplys and colleagues (2017) reported that patient-centred communication is useful when developing the relationship; it should validate and acknowledge the patient's experiences, as well as guide patients to rehabilitation, treatments and other services.

Building a strong patient-healthcare worker relationship across consultation meetings allows the healthcare worker to reinforce the diagnosis, while exploring the patient's understanding of their condition (Fouche et al., 2019). This is especially important as the patient-healthcare worker relationship should not end after the diagnosis has been established (Chen and LaFrance, 2016).

2.6.3 Barriers and Facilitators to care

Several included studies reported the potential barriers and facilitators patients may face when navigating diagnostic and treatment services for FND. Healthcare workers, acceptance of the diagnosis and support were deemed to be both facilitators and barriers to care. A lack of resources was found to be a major barrier to the clinical management of FND.

2.6.3.1 Healthcare workers and health services

As discussed previously, the attitudes of healthcare workers can have an impact on the patient’s acceptance of their diagnosis and their outcomes. Healthcare workers have been reported as both facilitators and barriers to the clinical management of FND. A lack of clinical knowledge has been found to be a major barrier for patients attempting to access services (Pretorius and Sparrow, 2015, Sawchuk et al., 2017), leading to patients having to visit several healthcare workers to receive an FND diagnosis (Pretorius and Sparrow, 2015). This lack of knowledge has led to patients being misdiagnosed and even receiving inappropriate interventions (Pretorius and Sparrow, 2015), leading to further strain on services to correct these errors. Pretorius (2016) reported that healthcare worker knowledge was a facilitator to treatment, with patients who visited knowledgeable healthcare workers were more likely to have a positive experience than those who saw a less knowledgeable healthcare worker.

The transition from diagnosis to treatment, and lack of multidisciplinary collaboration, are further barriers for patients when attempting to access services. Adams and colleagues (2018) found that the transition from diagnostic to treatment services is a complicated barrier to overcome. This was supported by Plioplys and colleagues’ (2017), who found that some neurologists believed that their only role in the clinical management of the disorder was to provide diagnostic assessments. Mental healthcare workers have been found to be reluctant in providing diagnostic and treatment services to FND patients (Plioplys et al., 2017), which may be in part due to mental health service access being limited (Sawchuk et al., 2017), or some specialty doctors (such as general practitioners or neurologists) perceiving psychological and psychiatric treatments for FND being futile. These barriers may lead to patients having delayed treatment due to: healthcare workers being unsure which service(s) should be involved in the assessment and treatment process; negative outcomes; and patients feeling abandoned by the clinical management process.

In contrast, a multidisciplinary team approach has been found to be an effective facilitator for caring for these patients (Aybek et al., 2013, Petrochilos et al., 2020). Mental health care provision within a neurology or epilepsy service has been found to be a facilitator to treatment, with benefits including improved outcomes, an increase in the likelihood of a patient accepting their diagnosis, and a reduction in stigma (Sawchuk et al., 2017).

2.6.3.2 Practical, emotional, and social support

Limited, or no support (from family members, friends, colleagues or healthcare workers) has been found to hinder diagnostic acceptance, treatment adherence and outcomes. Participants in Sawchuk and colleagues' (2017) study explained the importance of social support when navigating the clinical management process. Supportive family members and friends were found to make the process manageable for the patient (Pretorius and Sparrow, 2015, Rawlings et al., 2017), therefore acting as a facilitator. Similar findings have been reported in other studies, with many patients describing some healthcare workers as challenging, yet others proving to be a great resource in helping them cope throughout the diagnostic process (Pretorius, 2016, Pretorius and Sparrow, 2015).

2.6.3.3 Resources

Funding and medical insurance are major barriers to patients accessing healthcare, with studies from high-and low-income countries reporting similar issues. Pretorius and Sparrow (2015) found that although some of their patients had medical insurance, the insurance did not cover all their medical expenses. In addition, healthcare workers and healthcare services charged fees that were higher than the participants' medical insurance rates. These high fees led to patients being unable to afford access to healthcare services. This is supported by Tolchin and colleagues (2020), who reported that some participants struggled to access treatment due to poor medical insurance coverage. Healthcare system funding was found to be a further barrier, with one study reporting how a lack of resources caused an obstacle to patients being able to access appropriate care (Fouche et al., 2019).

2.6.4 FND Acceptance

Patients' acceptance of their FND diagnosis was discussed in a small number of survey and interview studies. Most reported patients' reluctance when accepting their diagnosis, with patients stating how they felt misunderstood or frustrated by the clinical management process.

2.6.4.1 Rejecting the FND diagnosis

Patients' reluctance to accept their FND diagnosis, or to outright reject their diagnosis, has been reported in several studies. Some patients were unwilling to accept their FND diagnosis even after it was confirmed by multiple assessments or healthcare workers (Adams et al., 2018). Possible reasons for why a patient may be reluctant (or reject their diagnosis) include: wanting to seek an alternative explanation for their symptoms (Adams et al., 2018); receiving conflicting information from healthcare workers (Bolton and Goldsmith, 2018); their own belief about the reason for their symptoms being incorrect (Bolton and Goldsmith, 2018); or a medical or neurological diagnosis has being missed (Fouche et al., 2019, Rosebush and Mazurek, 2011). This reluctance or rejection may lead to patients feeling angry and misunderstood, abandoned or thinking that others believe they have feigned their symptoms (Cottencin, 2014).

Traditional and cultural beliefs were found to be factors of a patient accepting or rejecting their FND diagnosis. Some patients reported that mental illness was a basis for possible medical conditions going against their belief system, and others believed their disorder was part of a ‘bigger plan’ by a deity (Pretorius and Sparrow, 2015). Furthermore, family members may also influence acceptance and treatment outcomes, as some assume the patient is malingering or that they control their functional seizures (Bermeo-Ovalle and Kanner, 2017, Klinke et al., 2019). These beliefs may lead to the patient becoming reluctant to accept their diagnosis and adhere to a treatment plan. However, traditional and cultural beliefs can also be a positive influence. One study found that prayers from the patient and family members were a coping strategy against the condition and were cathartic (Pretorius and Sparrow, 2015).

This reluctance or rejection may impact on the patient’s outcomes; it has been found that those who reject the diagnosis are less likely to complete treatment (Adams et al., 2018, Fouche et al., 2019, Rosebush and Mazurek, 2011) and have less successful outcomes when receiving psychiatric treatment (Rosebush and Mazurek, 2011). Conversely, as patients and their caregiver’s acceptance of the recommended treatment is more likely to lead to more successful long-term outcomes (Bermeo-Ovalle and Kanner, 2017). Therefore, healthcare workers should pay special attention to reluctant patients and give them more time to discuss the diagnosis (Baslet et al., 2015).

2.6.4.2 Accepting the FND diagnosis

Communicating the diagnosis in an accessible and informative way is key to a patient accepting their FND diagnosis (Klinke et al., 2019). Successful conversations can bring feelings of relief to the patient and is a requirement for the patient engaging in future treatment (Klinke et al., 2019, LaFaver et al., 2020a). However, it can be difficult for a healthcare worker to decide when to relay the diagnostic information. Klinke and colleagues (2019) reported how ensuring all healthcare workers (involved in the clinical management of FND) used the same terminology and metaphors, and found ways to give patients time to articulate their symptoms and disorder, led to patients being more likely to accept their FND diagnosis. A further study (O'Connell, 2017) found that patients who accepted that psychological factors may play a part in their diagnosis were more likely to see an improvement in their symptoms after treatment.

Although patients may accept their FND diagnosis, some do so begrudgingly. Rawlings and Colleagues (2017) reported that patients in their study remarked how their functional *seizures "would always be a part of their life, but hopefully, a smaller part*" (p.88). This reluctant acceptance was linked to the patient's symptom duration, with patients experiencing functional seizures for a longer length of time being more likely to feel this way.

2.7 Discussion

This study used scoping review methodology to identify, chart and synthesise findings from 162 records, which reported on the clinical management of FND. The included data have been documented by geographic area and setting, diagnostic method or treatment intervention, key findings, and also whether the record explored the perspectives of patients, caregivers, or healthcare workers on the clinical management of FND. The implications of this review (and the knowledge gaps emerging from the results) are reported below in relation to the research aims and objectives. In addition, more weighting has been given to studies with a stronger evidence rating (evidence levels are reported in Tables 3-5).

There is a great variability in the approaches to FND diagnosis and management (Asadi-Pooya, 2016). The included records revealed evidence on the positive and negative aspects of the clinical management of FND. The studies reviewed in this work were conducted worldwide; however, most of the included studies were conducted in North America and Europe. In addition, many were conducted in high income countries. Therefore, the findings may not be applicable globally.

2.7.1 Diagnostic methods to diagnose a patient with FND

Traditionally, FND was typically diagnosed by running tests to rule-out organic disorders (LaFaver et al., 2020a). However, from the studies included in this review, it is apparent that the use of rule-out tests is beginning to decline, and positive tests are increasingly being used to diagnose patients. This is also evidenced by the new wave of mechanism studies exploring the onset of functional symptoms and links between inflammation, biomarkers and FND. One recent research study exploring biomarkers and serum proteins found that neuropeptide Y and adrenocorticotropic hormone levels were the optimal combination of predictors for functional seizures, with over 90% accuracy (area under the curve = 0.980; (Miani et al., 2019). We may find that if future mechanism studies are conducted using more rigorous methods, biomarker and serum level tests may be used to assist in the diagnosis of FND.

Neurological examinations have been investigated as a diagnostic tool for FND, with vEEG being reported as the gold standard diagnostic tool (Devinsky et al., 2011, Sahaya et al., 2011, Whitehead et al., 2017). The included vEEG evidence is much stronger than other diagnostic tools, with several studies finding vEEG assessments able to discriminate between FS and epilepsy (Syed et al., 2011, Varone et al., 2020). Nežádal and colleagues' prospective study (2011) evaluated the use of vEEG with suggestive seizure provocation, and found that combining both approaches significantly contributed to an accurate FS diagnosis. Other studies studying neurological examinations have reported similar findings. One prospective study investigating whether resting-state fMRI could discriminate between FND and control patients (Wegrzyk et al., 2018) reported positive results with specificity, sensitivity and accuracy over 68%. While the study's generalisability is limited due to only including patients with functional motor symptoms (and not other symptoms such as FS), it highlights the usefulness of fMRI in the diagnosis of FND at the individual level. A retrospective case review investigated VEM for capturing functional seizures, and found that when monitoring patients for up to 7 days, 5 days of monitoring yielded the greatest number of diagnostic seizures and may be sufficient to diagnose up to 99% of FS patients (Foong and Seneviratne, 2016).

One blinded, prospective study (Biberon et al., 2020) evaluated the use of conversational analysis (involving two independent neurologists to blindly assess the patient interview) on French patients (reproducing the work originally conducted on German patients and then English and Italian patients) to differentiate between an FS or epilepsy diagnosis. Although the study utilised a small sample size (n = 32, of which only 13 presented with FS), it reported that conversational analysis had diagnostic value in differentiating FS from epilepsy with a good interrater reliability. It is important to note while conversational analysis may be accurate in differentiating between FS and epilepsy, research into the technique has only been conducted in European countries. Therefore, it may not be generalisable to other countries or cultures.

A small number of positive clinical signs have been found to be specific when testing for an FND diagnosis. Daum and colleagues' pilot study (2015) examined the clinical value of positive signs for FND diagnosis. After the examination of 40 video recordings (20 FND patients and 20 healthy controls), it was reported that six positive signs (Giveway weakness, Drift without pronation, Co-contraction, Splitting the midline, Splitting of vibration sense and Hoover’s sign) were found to be highly specific and ‘highly reliable’ for FND. In addition, these six signs had good to excellent inter-rater reliability.. While the study only utilised a small patient sample (therefore, not representative of the FND population) and was unable to conduct any sub-analyses for clinical presentations, it highlights the accuracy and usefulness of using positive signs when assessing a patient (and subsequently diagnosing) for FND. Hoover’s sign and drift without pronation sign have both been reported as very specific (Daum and Aybek, 2013, McWhirter et al., 2011). McWhirter and colleagues (2011) large, unblinded cohort study investigated the performance of Hoover’s sign in clinical practice, finding a moderate sensitivity (63%; 95% CI: 24 to 91) and a high specificity (100%; 95% CI: 97 to 100) for the positive sign. Although the study recruited a large sample of patients with suspected stroke (n = 337) to investigate the sign’s performance, only 8 of the patients included in the study were found to have functional weakness. Therefore, larger scale, blinded studies recruiting FND patients are needed to fully assess the positive sign. Lastly, the specificity of sternocleidomastoid (SCM) functional and platysma motor signs were investigated (Horn et al., 2017), finding that symmetrical platysma contraction (in conjunction with a head rotation weakness) was a predictor of conversion disorder. Therefore, positive clinical signs have merit in the FND diagnostic process.

Misdiagnosis was also explored in a small number of articles (n = 2). Two directions of research were found here. One article (van der Feltz-Cornelis et al., 2020) found that 12% of the FND/CD patients included in the study were misdiagnosed, as they turned out to actually suffer from an earlier unrecognised neurological or other somatic disorder. Another study (Walzl et al., 2019) examined how functional disorders were misdiagnosed as a neurological disorder and found that 2% (n = 48) of patients were misdiagnosed. Therefore, re-evaluating the diagnosis of chronic FND patients (to ensure they have not been misdiagnosed) is of great importance.

Although the included reviews generally provided support for the diagnostic methods typically used by services, most of the diagnostic methods studies included in this review were retrospective case reviews, cross-sectional studies or non-randomised prospective trials, and only recruited a small sample size. Therefore, the evidence reported should be interpreted with caution.

2.7.2 Intervention options used to treat FND

This review also explored treatment options for FND. Psychological therapies have been recommended as the main treatment to work through any psychological reasons for the onset of the disorder, and to reduce symptoms (Hingray et al., 2018). However, the main treatment type reviewed in this work was medication. Given that medication is the most investigated treatment, and that an effect was found, it is surprising that the three included clinical guidelines do not place any emphasis on prescribing medication, instead recommending the use of psychological and physical therapies to manage symptoms.

Two RCTs (Jafari et al., 2018; Ghanbarizadeh et al., 2018) examined the effectiveness of medication to reduce FND symptoms, with both reporting that haloperidol was effective. Jafari and colleagues' (2018) study reported haloperidol had a success rate of 91.5% in managing FND symptoms compared to midazolam's success rate of 64.3%. Ghanbarizabeh and colleagues study reported similar findings, with 90.4% of haloperidol patients and 91.5% quetiapine patients reporting symptom relief within 30 minutes. However, in both studies, patients in the haloperidol arm experienced more side effects than those randomised to the second arm of their respective study, indicating the potential safety issues of prescribing haloperidol to relieve FND symptoms. Further, neither study implemented a control arm nor had a long follow-up period. Therefore, it is difficult to establish the long-term effectiveness (or any potential issues) of the medications. One quasi-experimental study (Jain et al., 2020) investigated the effectiveness of medication (sertraline) combined with psychological therapy (CBT) versus just medication (sertraline) and found that combining both treatments was more effective in improving symptoms than individually. Further, sertraline alone was not found to be effective in reducing FND symptoms.

A wide range of studies examined the effectiveness of psychological therapies to treat FND, predominantly investigating CBT. The included CBT studies reported conflicting findings. Goldstein and colleagues (2020) conducted a large, pragmatic RCT (n = 368) comparing the effectiveness of CBT and care as usual (CAU), versus CAU alone for patients with a FS diagnosis. While the study found no statistically significant difference between the two groups at the 12-month follow-up timepoint, 9 of the 15 secondary outcomes were found to be significant ($p \leq 0.05$). These outcomes included global change (both self-rated and clinician rated), psychosocial functioning, and treatment satisfaction. Further, treatment compliance in the CBT group was high (75%). Although the study was limited by allowing the CAU patients to access any treatment (and therefore may be able to access psychotherapy, thereby skewing the results), these findings indicate that CBT may be an acceptable treatment for FND and FS patients and have a positive impact on perceptions of health and psychosocial functioning. In contrast, one pilot study and one quasi-experimental study found that CBT led to a reduction in FS frequency (Bajaj et al., 2017, Espay et al., 2019). Espay and colleagues' (2019) study also measured the response of neural correlates to CBT (via fMRI), finding improvements in decreased overactivity in the anterior cingulate/ paracingulate region. However, both studies only recruited a small number of participants (Espay et al., 2019, n = 40, Bajaj et al., 2017, n = 50) compared to Goldstein's fully-powered, large randomised controlled trial, showcasing that their seizure reduction rates may be due to small sample sizes. Dallocchio and colleagues' (2016) single-blinded, pilot study (n = 29) explored the effectiveness of CBT in conjunction with adjunctive physical activity (APA) versus CBT in FMD patients, and reported that both groups significantly improved over time, with no favourable effect from APA being found. While a reduction in depressive symptoms and anxiety was reported in the CBT group, no beneficial effect on other outcomes were found in the APA group. As the study only collected outcome measures at baseline and 12 weeks, the long-term effects of CBT and APA have not been established.

Psychoeducation and self-help websites were additional treatments that have been reported in this research area. One small, non-randomised study (Sarudiansky et al., 2020) investigated the effectiveness of psychoeducation groups, and found that the majority of participants reported a reduction in functional symptoms. Cope and colleagues (2017a) developed a 3-session psychoeducation group (built upon CBT) as part of their neuropsychiatry service. While only a small sample (n = 19) was included in the pre-post study, significant improvements in patient psychological distress and illness beliefs were reported, alongside a decrease in FS. Although no longitudinal data were collected, the findings indicate the psychoeducation group can be beneficial in FND treatment management. Gelauff and colleagues (2020) non-blinded RCT (n = 186) studied the effectiveness of internet-based self-help and education in addition to care as usual versus usual care only, finding no significant difference in improvement of self-rated health at the three- or six-month follow-up points. Interestingly, satisfaction of the website was high, with 86% of participants in the intervention group recommending it to other FND patients. While no significant difference was found, the online self-help website and education may still be a useful addition to support FND patients during their treatment due to its high satisfaction rate.

Hubschmid and colleagues' (2015) conducted an RCT comparing a brief interdisciplinary psychotherapeutic intervention (IPI) versus CAU, finding a statistically significant improvement in psychological and physical symptoms at the 12-month follow-up time point. Further, participants in the IPI group were less frequently readmitted to hospital (and have hospital stays) than those in the control group. While only a small number of participants were recruited to the study (n = 23), IPI may still be generalisable for all FND related symptoms as the treatment is patient tailored. A larger scale trial would be prudent to establish its effectiveness on FND symptoms.

One retrospective cohort study aimed to establish the feasibility of physiotherapy on reducing FND symptoms and found a statistically significant positive correlation between the number of sessions attended and clinical improvement (Maggio et al., 2020).

Lastly, Drane and colleagues' (2015) studied the effectiveness of a standardised treatment approach (a communication script, psychiatry consultation and FS educational documents) with or without weekly telephone follow-up appointments against unscripted diagnosis delivery. A statistically significant decrease in FS frequency was found at the 8-week follow-up timepoint for patients in both of the standardised treatment approach groups. Although the study utilised a small sample size (n = 37) and only had an eight-week follow-up, it highlights how a standardised approach to diagnosis improves clinical outcomes and can assist in decreasing FS frequency.

Similar to the diagnostic studies, the included records focusing on FND treatments were mainly retrospective cohort and case reviews, surveys and non-randomised trials. Although the treatment studies typically recruited more participants than the diagnostic studies, the majority were underpowered. Therefore, the evidence should be interpreted with caution.

2.7.3 Comparison of international FND clinical guidelines

As well as scoping the evidence on the clinical management of FND, this review also aimed to identify and compare international FND clinical guidelines. Although FND focused studies conducted globally were retrieved for this review, only three official guidelines were retrieved, all from European countries (The Netherlands: GGZ Standaarden, 2021; Denmark: Danish College of General Practitioners, 2013; Germany: Roenneberg et al., 2019). Thus, the information from the retrieved clinical guidelines cannot be generalised to a global setting. An optimal clinical pathway document from the National Neurosciences Advisory Group based in the UK (Edwards et al., 2019) was retrieved during the searching process, but was not included in this review. This is due to the document being a draft and not finalised during the time of writing.

All three guidelines promote a multi-disciplinary and integrative, stepped care approach for the clinical management of FND, which is supported by previous research stating that healthcare workers preferred a multi-disciplinary approach (de Schipper et al., 2014). In addition, each guideline emphasises the importance of the patient-healthcare worker relationship, and how careful and attentive listening and conscious proactive behaviour not only strengthens the patient-healthcare worker, but also reduces potential iatrogenic harm. These recommendations are evidenced by qualitative studies exploring the patient-healthcare worker relationship (Fouche et al., 2019, Plioplys et al., 2017).

While each guideline was developed using evidence-based studies, only the Dutch and German guidelines were recently updated with recent research and recommendations (the Danish guidelines were published in 2013, almost 10 years ago). Therefore, the Danish guidelines may be utilising outdated information.

This scoping review highlights the paucity of clinical guidelines for the management of FND. The evidence scoped and presented in this review may be of use for the development of future clinical guidelines.

2.7.4 Patient, caregiver and healthcare worker experiences and perspectives on the clinical management of FND

A small number of studies reported the experiences of patients, caregivers or healthcare workers about the clinical management of FND. From the scoped research, it appears that both healthcare workers and patient belief and support systems have a direct impact on patients’ experience of the clinical management of FND (O'Connell, 2017, Pretorius, 2016, Pretorius and Sparrow, 2015, Rawlings et al., 2017, Wyatt et al., 2014).

Conflicting results were found when exploring the confidence of healthcare workers involved in the clinical management of FND (Lehn et al., 2019, Sahaya et al., 2012), with some not feeling confident in discussing the diagnosis with patients. Two survey studies found that a large number of healthcare workers had a negative attitude towards patients presenting with functional symptoms (Lehn et al., 2019) or beliefs that patients had voluntary control over their functional seizures and that FND is a fake disorder (Sahaya et al., 2012). These findings are supported by Kanaan and colleagues (2011), where a minority of respondents stated that malingering and FND are similar disorders. These attitudes are concerning, as the healthcare workers may not be providing suitable and appropriate support to patients presenting with a functional disorder.

As stated previously, only a handful of studies have explored the experiences and perspectives of patients, caregivers or healthcare workers. Further research is needed in this area to establish how patients can be better supported throughout the diagnostic and treatment processes for FND.

2.7.5 Strengths and limitations

The current review used a rigorous approach to gather evidence to answer the research aims and objectives. The PCC framework detailed in Section 2.4.2 was used to develop the search strategy and the search strategy was piloted to ensure relevant studies were retrieved. In addition, a senior information specialist based in the Centre for Reviews and Dissemination (CRD) was contacted to quality check the search strategy.

The majority of the included studies were published in English; where possible, studies published in other languages were assessed and included (if applicable) if a member of the review team was fluent in the published language. Unfortunately, not all foreign language papers retrieved during the database searches were able to be included as they were unable to be translated due to financial constraints.

Both peer-reviewed and grey literature were included in this review; this was to ensure that relevant evidence would be chartered and synthesised. A consultation exercise (involving contacting patients, caregivers, and healthcare workers involved in the clinical management of FND for relevant records) was employed to gather any information that was potentially missed during the database searches.

As scoping reviews provide a narrative account of the body of literature, and do not focus on potential risk of bias, a formal quality assessment was not completed for this study. While a formal quality assessment is not necessary when conducting a scoping review, it the implication of this should be noted. Conducting a quality assessment assists in the understanding of how well (or transparent) included records have complied with methodological standards (Delavari et al 2023). Therefore, by not conducting a quality assessment, we cannot determine an included record’s potential risk of bias (whether their study design, their conduct of the study, or the conducted analysis). However, the quality of included articles was judged by the levels of evidence hierarchy set out by Glover and colleagues (2006; for more details see Section 2.4.4), and a note was written on the data charting form on the quality of each study to support the data synthesis (with more weight placed on the results of high-quality studies) and theme development. Although a large amount of literature was retrieved during the database searches, reference checking and consultation exercise, only a small number of high-quality articles met the inclusion criteria (n = 14).

It was originally planned that an independent second reviewer would be involved in the data charting process; however, due to constraints caused by the COVID-19 pandemic lockdowns, only the author conducted this process. However, the data charting form was piloted, and the PhD supervisors had an overview of the process.

All types of publications were included in this review to allow all records to be included if relevant. However, when synthesising the included reviews, it was discovered that much of the evidence reported was utilised from studies published in the early 2000s. The reviews, including studies published before the DSM-4 was developed, were given less weight to reflect the changes of the advised clinical management of FND between the different versions of the DSM.

2.7.6 Implications for research and clinical practice need

Currently, the management of FND presents a clinical challenge; there are limited laboratory-based diagnostic tests, and only a handful of treatments are being studied for effectiveness using RCT methodology. In addition, it is apparent that there is a lack of official clinical guidelines available for UK healthcare workers. Only three official guidelines were found during the searches, none of which were from a UK perspective. This may be one reason why patients face delays when undergoing the diagnostic processes as healthcare workers are unsure or not confident in how the process should go ahead. This review may be a useful document in the creation and development of future clinical guidelines as it provides an overview of recent FND diagnostic and treatment tools.

This review reveals a need for more rigorous and fully powered, prospective studies examining the diagnostic methods and treatments for FND. The review’s findings highlight that although some diagnostic methods and treatments (such as scripted diagnosis and intravenous haloperidol) show some effectiveness, a more multidisciplinary, holistic approach may be the future of clinically managing FND. This supports the findings from the thematic analysis, where effective communication, a positive patient-healthcare worker relationship, and clinical management between clinical teams were successful in the diagnosis and treatment of FND (Aybek et al., 2013, Petrochilos et al., 2020). Therefore, this review recommends that future research focuses on establishing the effectiveness of utilising a multidisciplinary approach for the clinical management of FND.

As discussed previously, the main diagnostic methods for FND typically involve exclusion, positive criteria and symptomology. However, new methods are being explored, including assessing for systemic inflammation, serum proteins and biomarkers. Currently, these methods are being used to assist in the diagnosis of FND but cannot be used as a stand-alone assessment. If proof of mechanism is found for these methods, it may have an impact on the future of diagnosing FND.

Lastly, it is evident that healthcare workers should be given adequate training on FND. The negative attitudes and stigma shown by healthcare workers to patients with FND incredibly concerning. However, it has been found that providing education to healthcare workers reduces negative attitudes towards functional disorders.

2.8 Conclusion

This review provides an overview of the evidence for the clinical management of FND. Remarkably, a large number of articles were retrieved, with 162 being included in this review. A wide variety of diagnostic tools and treatments were found, with more focus being placed on tests which confirm a diagnosis (such as positive clinical signs) than ‘rule-out’ tests. The most common treatment type found in this review was prescribed medication, with many of the medication studies reporting positive outcomes. In view of this finding, it is surprising that the clinical guidelines included in this review emphasise psychological and physical therapies, rather than prescribing medication to manage FND symptoms. Indeed, the Dutch guideline reports that there are no indications that pharmacological treatment is effective, yet two promising pharmacological studies were published (Ghanbarizadeh et al., 2018, Jafari et al., 2018) before the Dutch guidelines were updated in 2021.

There is a lack of high-quality evidence reporting on the diagnostic and treatment processes for FND (as judged by the levels of evidence hierarchy set out by Glover and colleagues (2006), indicating that more rigorous studies are needed.

This review reflects the need for official clinical guidelines for FND, providing healthcare workers and patients the support needed to navigate the process to diagnose and manage FND. The findings of this review may be useful for the development of future guidelines as it maps out the current research evidence into the clinical management of FND. This review recommends that future guidelines focus on utilising a multi-disciplinary approach to the clinical management of FND, including using diagnostic tools which confirm the diagnosis (such as positive clinical signs which have found to have high sensitivity and specificity) rather than methods which simply ‘rule-out’ other conditions. Prescribing pharmacological treatment where necessary, and shared decision-making between patients and healthcare workers should ensure more favourable outcomes for patients.

Chapter 3: Research Methods

Chapter one has provided a background into the key issues on the clinical management of functional neurological disorder (FND), and chapter two provided context on the existing FND research. This chapter describes how the overall research aims and objectives of this thesis were addressed through a mixed-method approach. The methods used in stage two of this thesis (Chapters 4 and 5) are detailed in this chapter. The scoping review methods (stage one) can be found in Chapter 2. The strengths and limitations of the overall PhD research study are included in the discussion chapter (Chapter 7).

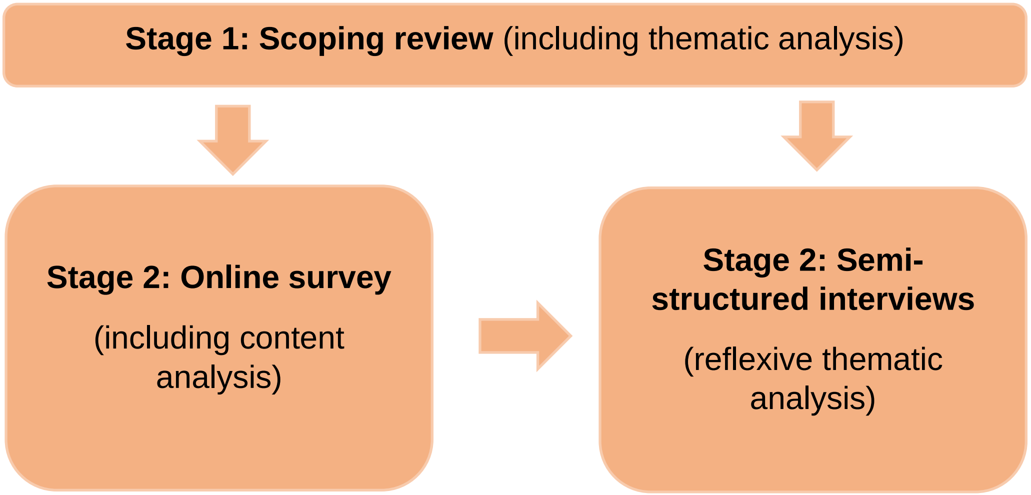
3.1 Rationale of utilising a mixed-methods approach

As the experiences and perspectives of those involved in the clinical management of FND are highly complex, no singular method would be able to fully understand and accurately report this phenomenon. Mixed-methods research involves taking the strengths of both quantitative and qualitative approaches in the collection, analysis and integration of data (Creswell, 2015). In addition, a mixed-method approach allows for a comprehensive understanding of a phenomenon rather than utilising one method alone, as it combines generalisable and representative data derived from quantitative research methods, with the depth provided from qualitative methods.

Mixed-method approaches are being increasingly used in healthcare studies (Guetterman et al., 2015), as they provide researchers with the opportunity to understand complex issues such as the lived experience of chronic illness, as well as diagnostic and treatment options in health services (Nicca et al., 2012, Raven et al., 2011). As this research aimed to identify how FND is clinically managed in UK services, alongside understanding patient needs throughout the clinical management process, utilising a mixed-methods approach was deemed both suitable and appropriate.

A two-stage approach was adopted for this thesis. This approach involved multiple methods of data collection, including a scoping review (stage 1), an online survey (stage 2) and semi-structured interviews (stage 2). Data analysis approaches included quantitative analyses for both the scoping review and relevant data from the survey, content analysis of the survey data, thematic analysis for the scoping review and reflexive thematic analysis of the semi-structured interviews. Figure 5 details the methods used throughout the PhD study and how each stage feeds into the next.

Figure 5: Study design methods flowchart



The methods used throughout stage two of this study will be detailed in this chapter. The scoping review methodology is detailed in Chapter 2.

3.2 Stage two methods

Stage two involved two phases:

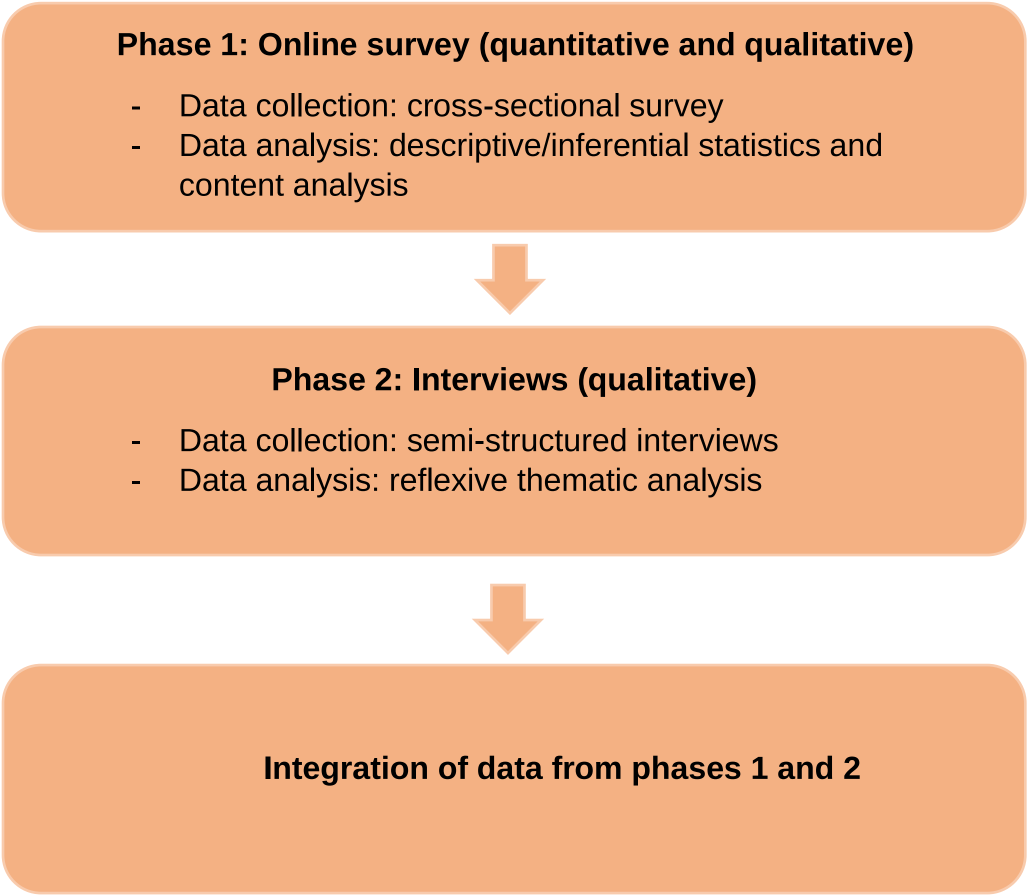
- Conducting an online survey (phase 1)
- Conducting semi-structured interviews (phase 2)

Both phases are detailed below in separate sections.

A mixed sequential explanatory research design was the most appropriate study design for stage 2. A sequential explanatory design utilises a two-phase approach, which begins with quantitative data collection and analysis in phase one, followed by qualitative data collected and analysed in phase two (Creswell & Plano Clark, 2018). The data from both phases are then integrated, allowing for a rich data analysis.

By using a mixed-methods design, the strengths of quantitative and qualitative methods are brought together to develop a greater understanding of the issue at hand. Figure 6 (below) details the study design for stage 2.

Figure 6: Stage 2 study design



3.2.1 Eligibility criteria

To be eligible to take part in the online survey or the semi-structured interviews, participants must have met the following criteria:

- Be:
  - A patient who has either:
    - Received a diagnosis or is undergoing diagnosis of FND
    - Suspected they have FND
    - Been turned away from accessing FND related services
  - An informal caregiver supporting an FND patient
  - A healthcare worker who works with FND patients
- Be aged 18 years or older
- Be able to speak and understand written and spoken English

Originally, it was planned that the thesis studies would be open to all adults, no matter what their spoken and/or written language was. However, due to a limited budget, the survey and interview questions were unable to be translated into other languages. In addition, there was no budget to pay for a translator for participants who could not communicate in English.

The decision to only include adult patients (aged 18 years and over) in this thesis was not made lightly. After discussions with the supervisory team, it was agreed that only adults would be included as the main supervisor would only be able to provide clinical advice and support for adult patients (as they are a psychiatrist specialising in adult patients). In addition to this, it was also thought that the sensitive nature of the topic at hand may be too distressing for children to discuss in great detail and at length. Therefore, with the lack of clinical support available from the author and supervisory team, it was deemed that it would be inappropriate to include child and adolescent patients in this work. However, while it should be acknowledged that the exclusion of children and adolescents in this thesis means their experiences and perspectives have not been captured, and that the findings from this work may not be applicable or generalisable to them, it does not mean that these experiences and perspectives are any less important than the adult patients who participated.

3.2.2 Phase One: Survey study

Phase one consisted of three comprehensive surveys for patients, healthcare workers and caregivers, who have been involved in the diagnosis and treatment of FND.

The objective of phase one was to map the current FND diagnostic and treatment processes utilised in NHS Trusts across the UK. In addition, phase one aimed to identify information to be included in the semi-structured interview topic guides that were used in phase two.

As discussed previously (Chapter 2), the clinical management of FND can be challenging for both healthcare workers and patients, due to the limited laboratory based-diagnostic tests and treatments available. Furthermore, there is a lack of FND clinical guidance available for healthcare workers, and there is also no official FND NICE guidance. This indicates that the clinical management of FND may vary between UK health services. The lack of guidance may also impact on the shared decision-making process between patients and healthcare workers, who may be unaware of specific diagnostic pathways or treatments.

There is also very limited evidence on how patients and their caregivers experience the clinical management of FND. The modest number of studies (such as Kanaan et al., 2011, O'Connell, 2017 and Rawlings et al., 2017) exploring this phenomenon only recruited a small sample size, or focused on one setting (e.g., accident and emergency). Thus, further research is needed to explore the experiences (both positive and negative) of healthcare workers, patients and caregivers involved in the diagnosis, treatment and care of FND.

This survey work was needed to document the current FND diagnostic tools and treatments used in the UK, in order to explore how FND patients are being assessed and treated, and establish whether the variety of tools and treatments being used across services have a different impact on the patient experience.

In order to complete this research, survey questions were developed for each participant group (patients, caregivers and healthcare workers). Sample size, question types and topics are detailed later in this section.

3.2.2.1 Sample size

Typically, the sample size for surveys (which aim to statistically analyse the derived data) is determined by performing a power calculation. This is to ensure that the data is representative of the population being studied. However, mixed-methods and qualitative-based surveys (containing open-ended questions) typically rely on data saturation to determine the overall sample size (Tran et al., 2017), or follow the sample size of previous work (Green and Thorogood, 2004). Data saturation can be determined as the point when sufficient data have been collected and any further collection would be unnecessary (Saunders et al., 2018). However, it must be acknowledged that while studies have found that data saturation for open-ended questions can be reached for studies recruiting over 150 participants (Tran et al., 2016), it may still be difficult, or even impossible (depending on the topic being studied) for a researcher to determine due to the nature of the data being provided by participants.

As the survey predominantly collected descriptive data (in terms of using descriptive statistics to analyse numerical data and asking people to describe their experiences and perspectives) and only used limited inferential statistics, a formal power calculation was not conducted. The survey study aimed to recruit at least 105 participants, with 35 from each participant group.

It is important that study recruitment is representative of the population of interest (Omair, 2014). This is because we need to ensure that the data collected from recruited participants can be generalised to the target population. To make sure the data collected in this research was as representative as possible, several strategies were employed. The survey was live for as long as possible (three months); this allowed for as many prospective participants to take part in the research. Recruitment was limited due to time constraints and University restrictions set in place due to the COVID-19 pandemic (detailed further in Section 3.8). However, to overcome these restrictions and ensure the sample was as representative as possible, the survey study was advertised widely over numerous social media platforms by the author and charitable organisations, and also by clinical specialty organisations through newsletters and bulletins. These advertisements ensured a wide range of participants were able to complete the survey. Lastly, the demographic information of participants was monitored regularly while the survey was live. This was to check that a wide range of people were completing the survey. Further recruitment information is detailed in the participant recruitment section. The inclusion/exclusion criteria for each participant group are described below:

Patient group (recruitment aim: n= 35)

Inclusion/exclusion criteria:

- Be a patient who has received a diagnosis or is undergoing diagnosis of FND, suspect that they have FND, or have been turned away from accessing FND-related services
- Be aged 18 years or older
- Be able to speak and understand written and spoken English

There are a variety of symptom types associated with FND. These include:

- Weakness or paralysis
- Abnormal movement (e.g., tremor)
- Swallowing difficulties
- Speech difficulties (e.g., dysphonia)
- Attacks or seizures
- Anaesthesia or sensory loss
- Special sensory symptoms (e.g., hearing disturbance)

(American Psychiatric Association, 2013)

It was aimed that at least five patients, who experienced at least one of the above symptoms, would be recruited to ensure the data collected were representative of the condition.

Healthcare workers (recruitment aim: n = 35)

Inclusion/exclusion criteria:

- Be a healthcare worker who works with FND patients, or has worked with FND patients within the last two years (this was to ensure the healthcare worker had current knowledge of FND diagnostic and treatment processes)
- Be aged 18 years or older
- Be able to speak and understand written and spoken English

Not all healthcare workers are involved in all stages of clinical management. For example, an occupational therapist would not usually be involved during diagnostic assessments, but may be involved in patient rehabilitation.

Phase one aimed to recruit healthcare workers, who are involved in the clinical management of FND, from the following health services:

- Neurology (e.g., neurologists)
- Physiotherapy (e.g., physiotherapists)
- Occupational therapy (e.g., occupational therapists)
- General practice (e.g., general practitioners (GPs), practice nurse)
- Accident & Emergency (A&E; e.g., consultant, nurse)
- Stroke wards (e.g., nurse, doctor)
- Psychology/Psychiatry (e.g., psychologist, psychiatrist, counsellor)

Caregivers (recruitment aim n = 35)

Inclusion/exclusion criteria:

- Be a caregiver to a person (or persons) with FND
- Be aged 18 years or older
- Be able to speak and understand written and spoken English

The sample size for the caregiver population was determined on two factors: potential burden and existing literature. It has been reported that caregivers have little dedicated time to participate in research, as they are managing multiple responsibilities (such as caregiving, work and family obligations; Murphy et al., 2007, Hazell et al., 2019). In addition, previous studies have reported low caregiver recruitment numbers (van der Feltz-Cornelis et al., 2022). Therefore, recruiting 35 caregivers was a sensible goal. To encourage caregiver recruitment, prospective participants were told they did not need to complete the survey in one sitting. Participants were able to complete the survey within two weeks from starting it.

3.2.2.2 Participant recruitment

Due to the limited time and budget available, non-probabilistic sampling (opportunistic sampling) was deemed to be the most appropriate recruitment strategy for phase one. Patients, healthcare workers and caregivers were all invited to participate in the survey. Examples of these invitations can be found in Appendix 5. Recruitment occurred online due to time constraints, and also to ensure a wide sample of respondents were approached. The survey link was shared via social media posts on Facebook, Twitter, online forums (such as Reddit) and FND support groups (such as FND Scotland and FND FrieNDS). FND Hope UK, the largest UK FND patient charity, were contacted to share the survey. Unfortunately, they were unable to promote the work as they were conducting their own patient survey at the time the current research would be live for participants to complete. The survey was also advertised via newsletters and in group meetings.

In addition, professional groups (such as the Neurological Alliance of Scotland and the Royal College of General Practitioners – Welsh branch) were contacted to advertise the survey to their members. Table 6 below provides further details on how the survey was shared.

Table 6: Information on how recruitment posts were shared

Who distributed the post?	**How was it shared?**	**How many times was it re-shared?**	**Who re-shared the post?**
Main author	Twitter	92	• Academics • Healthcare workers • General public • NHS Trusts • Support networks • University networks
Main author	Facebook	15	• General public • Healthcare workers • Academics
FND Action	Facebook	5	General public
Neurological Alliance of Scotland	Twitter	2	• Academics • NHS Trust
Main author	Reddit	N/A	N/A
FND Scotland (Facebook page)	Facebook	0	N/A
FND FrieNDS	Facebook	0	N/A
FND Awareness Group	Facebook	0	N/A
AHP FND Networking group	Added as an agenda point in their networking meeting	N/A	N/A
RCGP Wales	Added as an item on the weekly digest email	N/A	N/A
Megaphone Online (UOY online newsletter)	Added as an item on the online newsletter	N/A	N/A

The survey was designed to be completed online (via the Qualtrics platform) due to COVID-19 restrictions. However, participants were also offered the opportunity to complete the survey via post or phone/video conference for accessibility reasons. No participants completed the survey by post or phone/video conference.

As a thank you for completing the survey, participants were given the option to be entered into a prize draw (one £25 Love2shop voucher per participant group). An online random number generator (www.random.org) was used to determine which participants were the winners of the prize draw. The prize draw took place in September 2022, with winners notified via email.

3.2.2.3 Data collection

Three bespoke surveys were created, with questions developed using the current evidence that detailed current diagnostic and treatment processes. This information was derived from the completed scoping review (Chapter 2). Each survey was tailored specifically for the three population groups, and were piloted by patient and public involvement members from each relevant group (e.g., caregivers piloting the caregiver survey) who provided feedback. This feedback comprised language amendments (to ensure that survey questions were accessible) and consistency edits (e.g., ensuring the questions, which mentioned healthcare workers, referred to them as such, instead of using similar terms such as clinicians or health professionals). These minor changes were made before each survey was finalised, and then advertised for respondent completion.

Each survey was divided into three sections. The survey questions (asked in each section) varied depending on the participant group. Table 7 provides information on the questions that participants were asked in each section.

Table 7: Content of survey sections by participant group

Participant group	**Patients**	**Caregivers**	**Healthcare workers**
Section 1: Demographic/General Information			
Gender	✓	✓	✓
Age	✓	✓	✓
Ethnicity	✓	✓	✓
Geographic region	✓	✓	✓
Qualifications	✓	✓	✓
Work status	✓	✓	✓
Job title	✓	✓	✓
Main activity of work organisation/health service	✓	✓	✓
Hours worked per week	✓	✓	✓
Income/benefits received	✓	✓	
Housing and living arrangement	✓	✓	
Years in clinical practice			✓
Years worked with FND patients			✓
Number of FND patients seen per year			✓
Knowledge/expertise of FND			✓
FND specific training/education			✓
FND diagnosis	✓	✓	
Medical conditions	✓	✓	
FND symptoms experienced	✓	✓	
Date of FND diagnosis	✓	✓	
Accepted FND diagnosis	✓		
Reasons for FND onset	✓		
Duration of caregiving		✓	
Hours spent caregiving		✓	
Type(s) of caregiving provided		✓	
Experiences and/or perspectives of caregiving		✓	
Section 2: Diagnostic information			
Diagnostic assessments used/received	✓	✓	✓
Time from referral to FND diagnosis	✓	✓	✓
Types of support service provides to patients and caregivers during diagnosis process			✓
Healthcare workers involved in diagnostic tests	✓	✓	

Participant group	**Patients**	**Caregivers**	**Healthcare workers**
Services accessed	✓	✓	
Experiences of accessing services	✓	✓	
Information given during diagnosis	✓	✓	
Perspectives on whether services could have done things differently	✓	✓	
Support accessed (and wished to access) during diagnostic process	✓	✓	
Perspectives on support received from healthcare workers	✓	✓	
Section 3: Treatment information			
Treatments offered/received by service(s)	✓	✓	✓
Duration of treatments	✓		✓
Effectiveness of treatments offered/received	✓		✓
Treatment(s) that should be offered			✓
Healthcare workers that should be involved in the clinical management of FND			✓
Shared decision-making between patients and/or caregivers and healthcare workers	✓	✓	✓
Perspectives on whether new approaches/treatments should be implemented into services			✓
Any other comments	✓	✓	✓

The patient and healthcare worker surveys were split into demographic, diagnostic and treatment sections. The caregiver survey asked respondents for information pertaining to demographic information, the type of support given to the person to whom they provide support, as well as clinical management information.

The demographic information included questions on age, gender, ethnicity, work status and education. The Office for National Statistics (ONS) guidance on collecting demographic data was followed when developing these questions (ONS, 2021). Healthcare worker respondents were asked to provide demographic information on their job title and years worked in clinical practice. To determine the representativeness of the data, patient respondents were asked for their geographic location and the services they were currently accessing.

All respondents were given the opportunity to report any thoughts they may have had about their experiences and perspectives on FND. Details of the contents of the survey are provided below.

3.2.2.3.1 Patient survey information

Patient respondents were asked a series of questions relating to previous illnesses, childhood history, and diagnostic and treatment processes. The patient survey aimed to explore patient experiences of the clinical management of FND, and also identify patient needs. In addition, it aimed to gather data relating to previous illnesses (such as having an infection before or during the time of diagnosis), in order to enable an exploration of the possible reasons for symptom onset.

Patient respondents were asked to provide details on the healthcare workers who worked with them during the diagnostic process (for confidentiality reasons, only job titles were requested) and which (if any) services were involved. Information was also requested on the type(s) of treatments or support they had received since diagnosis.

3.2.2.3.2 Caregiver survey information

Caregivers of people with a diagnosis of FND were also invited to participate in the survey study. The survey included questions asking for information on the person they provide care for (such as age of diagnosis [if known], presenting symptoms etc). Caregivers were asked for their experiences of being a caregiver, and the diagnostic and treatment processes used in the clinical management of FND.

3.2.2.3.3 Healthcare worker survey information

The healthcare worker survey focused on how they and their current (and if applicable, previous) service assesses and treats patients with FND. Healthcare workers were also surveyed on their experiences of working with patients with FND, and whether they felt new approaches need to be implemented into services to support those (alongside caregivers and healthcare workers) with the condition.

For each assessment that a healthcare worker confirmed having used in the previous two years (in relation to FND), they were requested to provide information regarding how many patients they had provided the assessment(s) to, the source of referral, and what training and supervision they had received to deliver the assessment. Similar information was collected for any treatments that the healthcare worker confirmed as having used. The Template for Intervention Description and Replication checklist (TIDieR; Hoffmann et al., 2014) was followed to gather information relating to treatments.

3.2.2.4 Survey administration

The three surveys were self-administered (Lavrakas, 2008) and completed online via the Qualtrics survey platform, Version XM, between November 24th, 2021 and March 28th, 2022.

3.2.2.5 Data Analysis

The surveys collected both quantitative and qualitative data. Data collected from the surveys were used to identify issues for further exploration in the qualitative interviews, which were conducted in phase two. All survey respondents were asked if they would like to participate in the interview study, and if so, were subsequently asked to provide their contact details. Of the 319 survey respondents, 229 agreed to be contacted and 56 were invited to participate in the interview study. Information provided by the survey respondents was kept confidential and secured on an encrypted database stored at the University of York.

3.2.2.5.1 Quantitative Analysis

The survey collected nominal data and was analysed using SPSS v26 (IBM Corp, 2017). Barring the demographic data, each population group was analysed and reported separately, as each group was asked questions relevant to their population (e.g., patients were asked for information regarding their diagnosis). Descriptive statistics were used to analyse the data. Categorical data were presented with frequencies and percentages. Continuous variables were presented with mean and standard deviation (SD) scores. It was deemed that if inferential statistics could be conducted on the data, SPSS would be used.

Demographic data were analysed and compared to ensure it were representative of the FND population. This was determined by analysing age (the peak incidence of FND occurs between 35-50 years; Carson and Lehn, 2016), variety of FND symptoms reported (detailed earlier in this section) and gender (typically, women are three times more likely than men to be affected by FND; Bennett et al., 2021). It was planned that if the data collected were not representative of the FND population, the survey would remain live to recruit further participants. After analysing the data, it was determined that the patient data were representative of the UK FND population, as the majority of patient respondents were female (85%), aged between 35-54 years (48.2%), and all FND symptoms listed in the DSM-5TR (listed earlier in this section) were reported by at least 15% of participants.

3.2.2.5.2 Qualitative Analysis

A number of questions included in each survey focused on gathering data relating to respondents' experiences of the clinical management of FND. It was planned that if enough data were provided in the survey responses, qualitative data derived from the free text boxes would be analysed using a content analysis approach (Krippendorff, 1980).

The responses from the following survey questions were included in the content analysis:

Patients

- How did you feel accessing diagnostic services?
- Did you feel that you needed to access diagnostic services?
- What were your experiences of accessing services for FND diagnosis?
- Do you have any thoughts on whether the services could have managed your diagnosis better/differently?
- Do you have any thoughts on whether healthcare workers were supportive during the diagnostic process?
- What were your experiences of undergoing treatments?

Healthcare workers

- Do you think the process your service uses for diagnosis is suitable?
- Does your service involve patients and caregivers in decision-making?
- Are there any experiences you would like to share regarding working with patients with FND?
- Do you think new approaches/treatments should be implemented into services?

All respondents

- Are there any other experiences you would like to share?

Content analysis is a qualitative method which provides a representation of facts, as well as new knowledge and insights, by examining and analysing texts and/or documents (Elo and Kyngas, 2008, Krippendorff, 1980). Content analysis is a replicable and systematic method, which uses specific coding rules that allows for inferences to be made; It is possible to conduct whenever a physical documentation of a communication can be accessed (Mills et al., 2010). These document types may include speeches, books, historical documents, interviews, lectures and manifestos. Content analysis was an appropriate method to analyse the open-ended survey data, and it allowed for the data to be explored and mapped.

There are two divisions of content analysis: quantitative content analysis and qualitative content analysis. Quantitative content analysis involves establishing words/concepts and then counting the frequency in which those words/concepts appear in the document(s) being analysed (Mills et al., 2010). However, this basic approach may overestimate the concept or word’s importance, especially if the concept or word has multiple meanings. Qualitative content analysis involves the systematic investigation of documents, using categorising and coding concepts. Although qualitative content analysis may not include a frequency count, it has been suggested that quantitative and qualitative content analysis can be combined, with the researcher(s) quantifying the frequency of words/concepts in the included documents, and also interpreting the documents’ content (Hsieh and Shannon, 2005). This combination of quantitative and qualitative content analysis was utilised for the analysis of the survey data.

3.2.2.5.3 Demographic data

Demographic data were analysed. Table 8 presents the demographic data collected for each group.

Table 8: Survey study - demographic data collection

Question	Type of question asked to collect data	Type of data collected	Scales used
% of respondents in each group	Single choice	Categorical	Nominal
Age (including mean and SD)	Single choice	Continuous	Ratio
Gender	Single choice	Categorical	Nominal
Geographic region	Single choice	Categorical	Nominal
Ethnicity	Single choice	Categorical	Nominal
Work status	Open ended	Categorical	Nominal
Hours worked	Single choice	Continuous	Nominal
Qualifications	Multiple choice	Categorical	Ordinal
Area type (rural/ suburban/ urban)	Single choice	Categorical	Nominal

3.2.2.5.4 Economic data

The survey collected economic data from patients and caregivers. Table 9 contains the information used to determine the economic status of the respondents.

Table 9: Survey study - economic data collection

Question	Type of question asked to collect data	Type of data collected	Scales used
Qualifications	Multiple choice	Categorical	Nominal
Job title	Open ended	Categorical	Nominal
Income type	Multiple choice	Categorical	Nominal
Current residence type (e.g., privately rent/own home)	Single choice	Categorical	Nominal

These data were compared to geographical area, symptoms, diagnostic tools and treatment tools, which were compared using a descriptive analysis.

3.2.2.5.5 Patient data analysis

Table 10 reports the data included in the patient data analysis.

Table 10: Survey study – patient descriptive data collection

Question	**Type of question asked to collect data**	**Type of data collected**	**Scales used**
Functional disorder diagnosis	Multiple choice	Categorical	Nominal
Any other medical diagnoses	Open ended	Categorical	Nominal
Date of diagnosis	Open ended	Continuous	Nominal
Agreement of FND diagnosis	Single choice	Categorical	Nominal
FND symptoms experienced	Multiple choice	Categorical	Nominal
FND aetiology	Multiple choice	Categorical	Nominal
Healthcare worker(s) involved in diagnostic testing	Multiple choice	Categorical	Nominal
Service(s) patient visited when undergoing diagnostic tests	Multiple choice	Categorical	Nominal
Which healthcare worker(s) gave the FND diagnosis	Single choice	Categorical	Nominal
Diagnostic tool(s) used to assess patients	Multiple choice	Categorical	Nominal
Treatment(s) used to support patients	Multiple choice	Categorical	Nominal
Healthcare workers providing enough diagnostic information to patients	Closed ended	Categorical	Nominal
Duration of time from first reporting symptoms to diagnosis	Single choice	Continuous	Interval

3.2.2.5.6 Caregiver data analysis

Table 11 reports the data included in the caregiver data analysis.

Table 11: Survey study - caregiver descriptive data collection

Question	**Type of question asked to collect data**	**Type of data collected**	**Scales used**
Relationship with the FND patient	Single choice	Categorical	Nominal
Type of diagnosis the patient received	Multiple choice	Categorical	Nominal
Date of diagnosis	Single choice	Continuous	Interval
Diagnostic test(s) undertaken by the patient	Multiple choice	Categorical	Nominal
Treatment(s) undertaken by the patient	Multiple choice	Categorical	Nominal
Experiences of interacting with healthcare workers and services	Open ended	Categorical	Nominal
Duration of care provided	Single choice	Continuous	Interval
Hours (per week) spent providing care	Single choice	Continuous	Interval
Type of support provided	Multiple choice	Categorical	Nominal
Experiences of providing care	Open ended	Categorical	Nominal
Support groups accessed by caregiver	Multiple choice	Categorical	Nominal

3.2.2.5.7 Healthcare worker analysis

Table 12 reports the data included in the healthcare data analysis.

Table 12: Survey study - healthcare worker descriptive data collection

Question	Type of question asked to collect data	Type of data collected	Scales used
Job title and occupational group	Open ended	Categorical	Nominal
Hours worked per week	Single choice	Continuous	Interval
Years in practice	Single choice	Continuous	Interval
Service type	Open ended	Categorical	Nominal
Years working with FND patients	Single choice	Continuous	Interval
Amount of FND patients seen by service per year	Single choice	Continuous	Nominal
Knowledge/expertise rating of FND	Single choice	Categorical	Nominal
Education/training received about FND and diagnosis/treatment	Open ended	Categorical	Nominal
Diagnostic tests provided by service	Multiple choice	Categorical	Nominal
Diagnostic tests deemed necessary	Single choice	Categorical	Nominal
Average duration of time from referral to diagnosis in service	Single choice	Continuous	Nominal
Type of support provided by service to FND patients and caregivers	Multiple choice	Categorical	Nominal
Treatment types provided by service	Multiple choice	Categorical	Nominal
Treatment types deemed effective and/or necessary	Multiple choice	Categorical	Nominal
Healthcare workers being involved in the diagnosis/treatment of FND	Single choice	Categorical	Nominal

The specific survey questions can be found in Appendix 6.

The utilised content analysis approach was directed content analysis (Hsieh and Shannon, 2005), and was both deductive and inductive. Firstly, the words/concepts, which were categorised, were established using a priori coding; the categories were chosen from the scoping review (reported in Chapter 2) and the questions from the survey study. This was because the information (presented in the scoping review) and the survey questions (from assimilated current evidence in the topic area) were both up to date. The words/concepts, that were derived from the scoping review and questions, are presented in Table 39 (in Chapter 4). The words/concepts are presented along with the themes derived from the conducted content analysis.

Once this step was completed, the text provided in the survey study was read multiple times. This was because of recommendations, stating that included data should be read and re-read, to allow for the researcher(s) to gain an understanding, and also be fully immersed in the text (Erlingsson and Brysiewicz, 2017). The survey text was then sorted into manageable ‘meaning units’ (Bengtsson, 2016), which usually consist of smaller paragraphs or sentences. These units were then coded in relation to the words/concepts identified in the scoping review results and survey questions. To ensure reliability and duplicability, a coding list explaining each code was developed. The developed coding list for this work is reported in Appendix 7.

Once the data were sorted into meaning units, the original survey text was re-read to check if any unsorted text should be included in the analysis. Meaning units were then grouped into themes and sub-themes relating to the original words/concepts derived from the scoping review. The frequencies of the words/concepts in each theme were counted, with a ‘key word in context’ search following the frequency count, in order to check the consistency of the usage of the included words/context (Mills et al., 2010). This allowed the author to see which themes were the most reported in the survey text. NVivo software (V.12) was used to conduct the analysis. Participant responses to the questions (listed in Section 3.2.2.5.2) were uploaded to NVivo. The themes (derived from the scoping review and survey question data) were entered as nodes. When each response was read, it was coded into the relevant node. Following that, they were re-read to be immersed in the data. After this immersion, subcodes were created and added under the relevant node.

To increase the validity of the analysis, two researchers were involved. The author conducted the analysis, and the second researcher reviewed the original text and results to ensure they were both logical and reasonable (Bengtsson, 2016).

3.2.3 Phase Two: Interview study

Phase two involved conducting semi-structured interviews with patients, healthcare workers and caregivers on their experiences of the clinical management of FND. Although there are a wide range of interview types (such as structured or standardised interviews, unstructured interviews and focus groups), it was decided that semi-structured interviews were the most appropriate qualitative method for phase two, as the use of a topic guide ensured the interviews were consistent, while also allowing for some flexibility for each participant to share their experiences and perspectives (Jamshed, 2014).

The objectives of phase two were to:

- Explore the lived experience of patients diagnosed with FND
- Understand the experiences of caregivers providing support to people with FND
- Understand the diagnostic processes and treatments for FND
- Understand the attitudes and beliefs of healthcare workers working with patients diagnosed with FND
- Identify any potential triggers for the onset of FND

3.2.3.1 Study design

Braun and Clarke (2013) state that qualitative research refers to the *"application of qualitative techniques within a qualitative paradigm"* (Braun & Clarke, 2013, p.4). This definition of qualitative research is also known as 'big Q' research. Contrary to this, 'small q' research is not based within a paradigm, and only focuses on qualitative research data collection and/or analysis ('research techniques'). It is prudent to focus on 'small q' and 'big Q' research, as both occur in this thesis. While phase two sits within big Q research, the content analysis conducted in phase one and the thematic analysis presented in Chapter 2 fall under small q research, as they only focus on research techniques.

Phase two used a qualitative research design involving individual, semi-structured interviews. The SAGE Handbook of Social Research Methods (Alasuutari et al., 2008) and Bryman's (2016) Social Research Methods texts were closely followed, to ensure that the semi-structured interviews were conducted in a professional and calm manner. For example, Bryman (2016) recommends knowing the schedule of the interview, to alleviate the potential interviewer from being flustered, due to being unsure about upcoming questions. In addition, the text also provides advice on rapport building (between the interviewer and interviewee), how to order interview questions, and ensuring questions and instructions are clear, so that they are easily understood by the interviewees. This advice was followed by the author when conducting each interview. To ensure phase two was conducted robustly and transparently, the study followed and was reported commensurate with the consolidated criteria for reporting qualitative research (COREQ; Tong et al., 2007).

3.2.3.2 Sample size and participant recruitment

Interviews were conducted in the UK with patients who have a diagnosis of FND, caregivers and healthcare workers involved in the clinical management of FND. Qualitative studies tend to recruit a small number of participants compared to quantitative research, due to the richness of the data collected and because it is in-depth information(Ritchie and Lewis, 2003, Ritchie et al., 2013). Braun and Clarke (2013) recommend that small interview studies recruit between 6-10 participants. As this study included three different population groups, it was planned that approximately 30 participants (10 patients, 10 caregivers and 10 healthcare workers) would be recruited to the study, to ensure the likelihood of a wide range of experiences being collected. As the study was exploring the lived experiences of a health condition, there was potential for participants to become emotional or distressed during their interview. Ethical considerations of the study are presented in Section 3.7.

Participants were predominantly recruited via purposive sampling from phase one respondents, to ensure that a wide range of experiences from a variety of people (such as those from different genders, age ranges and population types [e.g., caregiver]) would be collected during the interviews. The participants recruited via purposive sampling had given prior consent to be contacted when they completed the survey study. It was planned that if enough participants could not be sought via purposive sampling, opportunistic sampling would occur to aid recruitment. This involved recruiting via advertising on social media, online support forums, word of mouth by healthcare workers and services, and through FND charities and organisations (such as FND Action UK and FND Hope UK).

Of the 319 survey participants, 229 (71.8%) agreed to be invited to take part in the interview study. 56 (24.5%) participants were invited (caregivers n = 20, healthcare workers n = 18, patients n = 18), 20 (35.1%) participants agreed (caregivers n = 8, healthcare workers n = 4, patients n = 8) and one (1.8%) declined to be interviewed due to having no availability (caregiver n = 1). The remaining 35 (62.5%) did not respond to their invitation. Seven participants (25%; healthcare workers n = 5, patients n = 2) were recruited via word of mouth and Twitter. Further demographic information on phase two participants can be found in Table 41. All prospective participants were sent an invitation to participate in the study, alongside the study’s information leaflet, via email (Appendix 14).

As a thank you to participants for completing the interviews, participants were given the option to be entered into a prize draw (£25 Love2shop voucher per participant group) at the end of the phase two recruitment period. Prize draw winners were notified in November 2022 via email.

3.2.3.3 Data collection

28 in-depth, individual semi-structured interviews were conducted by the author to explore the lived experience and attitudes of participants, caregivers and healthcare workers on the clinical management of FND. Interviews were able to take place in person, by telephone or by videoconference (e.g., Zoom) at a time convenient for the participant. Participants were able to choose how their interview was conducted; all 28 interviews took place via telephone or Zoom. While most participants took part in the previous survey study, no relationship was established prior to the interviews taking place. Informed consent was obtained before the start of the interview, and participants were notified that the information they provided would remain confidential (unless information was disclosed that someone was at risk of harm, or information of misconduct was disclosed); any identifying information would be removed from the transcript as well as any subsequent publications. In addition, participants were given a background on the author and the reasons for why she conducted the research. It was estimated that each interview would last for approximately 45-60 minutes. The interviews were conducted in English and were recorded using Zoom. Ethical approval was sought from the University of York Department of Health Sciences Research Governance Committee (Appendix 8).

Bespoke topic guides were developed for each population group of interest using data collected from phase one. PPI representatives (comprising a patient and a caregiver) were consulted to ensure the questions were relevant and could be clearly understood by participants. These topic guides can be found in Appendix 9. Pilot interviews were conducted to ensure the topic guides were suitable. After the pilot interviews took place, minor amendments were made to the questions in the patient topic guide, in order to improve the flow of the patient interviews.

Prospective participants were contacted three times over a one-month period, to give them sufficient time when deciding whether they wished to take part in the study. Once all willing participants were interviewed, recruitment ceased.

3.2.3.4 Data Analysis

The recording from each interview was transcribed verbatim within 72 hours of the interview taking place. All 28 interviews were transcribed by the author. The author continuously reflected on how their own experiences and worldview may impact on the interpretation and analysis of the data collected, and used a reflexive diary to record reflections. A sample of the reflexive diary can be found in Appendix 10.

3.2.3.4.1 Rationale for analysis method

As discussed previously, this thesis utilised a mixed-method design to ensure that the clinical management of FND, and the lived experiences of patients with FND, were fully understood. Stepping away from early definitions of mixed-methods research (defined as merely involving both quantitative and qualitative methods to study phenomena), Creswell and Plano Clark (2018) describe mixed-methods research as encompassing all parts of the research study, and that there are four philosophical 'worldviews' that influence mixed-methods research. These worldviews include the:

- Transformative (the belief that research should be interlinked with political agenda to enable social oppression to be challenged; Mertens, 2010)
- Pragmatic (the belief that there are several realities, and the world is not an absolute unity; Weaver, 2018)
- Constructivist (the belief that there is no single truth or reality, therefore reality needs to be interpreted; Crotty, 1998)
- Postpositivist (also known as the 'scientific method' (Creswell, 2014), where positivism is rejected, and absolute truth can never be discovered; Phillips and Burbules, 2000).

The pragmatic worldview was deemed to be the most appropriate paradigm to underpin this research for numerous reasons. Both the survey and interview studies involved different population groups (patients, caregivers and healthcare workers), who each had their own experiences and reality of FND and its clinical management. As the pragmatic worldview is not committed to any one reality, and as research occurs in many different contexts (such as social and political contexts), it is appropriate for this research as each population group has their own reality of FND.

In addition, this worldview allows a researcher to use the most suitable methods when addressing research problems and questions as necessary (Weaver, 2018). As a mixed-methods approach was needed to fully explore and understand the aims of this work (and the restrictions put in place due to the COVID-19 global pandemic), pragmatism was the most suitable worldview to support this work.

This second phase used a qualitative research design using individual, semi-structured interviews. There is a wide range of qualitative methods, which can be used to analyse the interview data, including interpretative phenomenological analysis (IPA) and discourse analysis. IPA is a participant-centred approach and aims to depict the participant's lived experience, based on their own world and how they make sense of their lived experience in the context of their personal and social worlds (Smith and Nizza, 2021). However, as IPA is more suitable for more complex research involving up to 10-12 participants, and may also include dyad/triadic participants (such as a parent and their child; Larkin et al., 2019, Smith and Nizza, 2021), it can be determined that it is not the most fitting method for the interview analysis (due to the interview study aiming to recruit approximately 30 participants). Similarly, grounded theory would not be a suitable method to analyse the interview data, as the participants were only interviewed once. Additionally, the aim of the interview study was to understand the lived experience of those involved in the clinical management of FND, not to develop a new theory (Bryant and Charmaz, 2007).

Thematic analysis is a further qualitative method. Thematic analysis is not just one singular method, but contains three different varieties (Braun and Clarke, 2019):

- Codebook (a rigorous method involving the process of developing a set of codes, or a codebook, to identify themes)
- Coding reliability (which involves multiple researchers identifying codes and categorising them into predetermined themes)
- Reflexive thematic analysis

Reflexive thematic analysis (RTA) is a subjective and iterative method, which uses themes to describe the lived experience of particular groups; it posits that the themes derived from the dataset are underpinned by the researcher’s previous assumptions, knowledge and beliefs (Braun and Clarke, 2021). RTA has been found to be well suited when analysing research that explores the experiences of accessing health services or receiving sensitive diagnostic information (Shannon et al., 2022, Warner and Groarke, 2022). With this in mind, the most appropriate analysis method for this interview study was RTA.

3.2.3.4.2 Analysis method

Traditionally, the quality of a piece of research is judged on the validity, reliability and objectivity of the data and analysis. However, as qualitative research is subjective in nature, Lincoln and Guba (1985) developed an alternative set of criteria to judge the quality of qualitative research: confirmability, dependability, transferability and credibility. Quality checks in qualitative research have been contested (Stenfors et al., 2020), with recent research stating that checklists such as the Consolidated Criteria for Reporting Qualitative Research (COREQ) or Standards for Reporting Qualitative Research (SRQR) may be more appropriate indicators of quality than Lincoln and Guba’s (1985) criteria (Stenfors et al., 2020). To ensure the quality of the analysis, both Lincoln and Guba’s

(1985) criteria (where appropriate) and the COREQ checklist (Tong et al., 2007) were followed (Appendix 11).

Dependability relies on the researcher to account for, and describe any changes to the research, as well as how these changes affected the research. To meet dependability criteria, a document was created to log the analytical process; an audit trail was kept, therefore ensuring the analysis was trustworthy (Nowell et al., 2017). The log also assisted in the write-up process. Confirmability is the degree to which the study's findings can be confirmed by another person. While it would be sensible to have the codes and analysis checked by a second researcher (to ensure the themes represent the data collected from the interviews), Braun and Clarke (2021) recommend only one coder. This is because RTA's purpose is to gain a more nuanced insight into the data. Credibility refers to how believable, or credible, the study's results are from a participant's point of view. All participants were sent a copy of their interview transcript, to ensure the transcript's accuracy and that it captured both their perspectives and experiences. Lastly, transferability is concerned with whether the study results can be transferred to other settings or contexts. To meet transferability criteria, the author ensured that the context of the research and its assumptions were described in detail, to ensure any future 'transfer' of the study data and results could be made sensibly.

The guideline set out by Braun and Clarke (2021) was followed when analysing the interview transcripts. The analysis was conducted using an inductive approach, as it allowed the data to determine the themes (Braun and Clarke, 2021). Each of the six steps followed are detailed below.

Stage 1: Data familiarisation

Each transcript was read closely three times, with the first reading taking place while listening to the audio recording of the interview. This was to assist in data immersion and aid with recall, as well as checking the transcript for any inaccuracies. Before taking part in the interview study, participants were informed that audio recordings and transcripts would be stored on a secure and encrypted hard drive at the University of York for three years after the study closed (as recommended by the University of York Department of Health Sciences research governance committee).

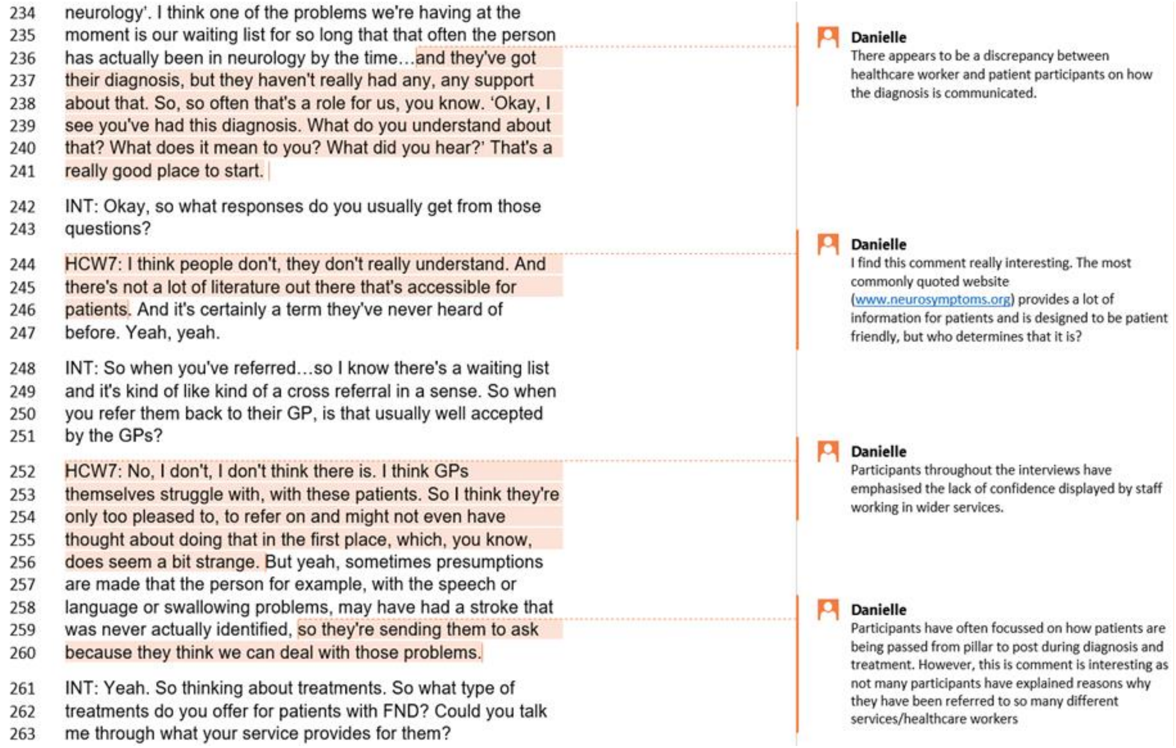
While listening/reading each interview, notes were written on the interview transcript. These notes included:

- The author's responses to the data

- Things of potential interest to the analysis
- Ideas to explore when coding

Each transcript was critically and analytically read by the author, with the author also keeping in mind any assumptions, that underpinned their initial reactions when reading the data. These assumptions included keeping notes on data that seemed (un)familiar or surprising, and why the researcher was reacting to the data in the transcript in a particular way. An example of the data familiarisation can be found in Figure 7.

Figure 7: Data familiarisation example



neurology'. I think one of the problems we're having at the moment is our waiting list for so long that that often the person has actually been in neurology by the time…and they've got their diagnosis, but they haven't really had any, any support about that. So, so often that's a role for us, you know. 'Okay, I see you've had this diagnosis. What do you understand about that? What does it mean to you? What did you hear?' That's a really good place to start.

INT: Okay, so what responses do you usually get from those questions?

HCW7: I think people don't, they don't really understand. And there's not a lot of literature out there that's accessible for patients. And it's certainly a term they've never heard of before. Yeah, yeah.

INT: So when you've referred…so I know there's a waiting list and it's kind of like kind of a cross referral in a sense. So when you refer them back to their GP, is that usually well accepted by the GPs?

HCW7: No, I don't, I don't think there is. I think GPs themselves struggle with, with these patients. So I think they're only too pleased to, to refer on and might not even have thought about doing that in the first place, which, you know, does seem a bit strange. But yeah, sometimes presumptions are made that the person for example, with the speech or language or swallowing problems, may have had a stroke that was never actually identified, so they're sending them to ask because they think we can deal with those problems.

INT: Yeah. So thinking about treatments. So what type of treatments do you offer for patients with FND? Could you talk me through what your service provides for them?

Danielle
There appears to be a discrepancy between healthcare worker and patient participants on how the diagnosis is communicated.

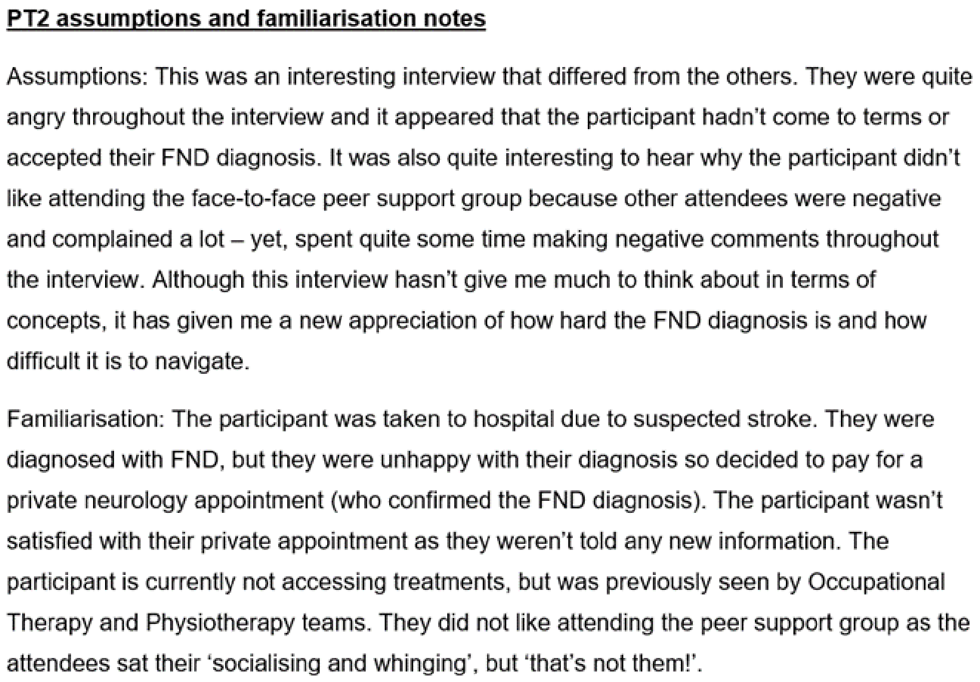
Danielle
I find this comment really interesting. The most commonly quoted website (www.neurosymptoms.org) provides a lot of information for patients and is designed to be patient friendly, but who determines that it is?

Danielle
Participants throughout the interviews have emphasised the lack of confidence displayed by staff working in wider services.

Danielle
Participants have often focussed on how patients are being passed from pillar to post during diagnosis and treatment. However, this is comment is interesting as not many participants have explained reasons why they have been referred to so many different services/healthcare workers

Once each interview was read and re-read multiple times (and assumptions described), familiarisation notes were written. An example of these notes can be found in Figure 8.

Figure 8: Example of assumptions and familiarisation notes



PT2 assumptions and familiarisation notes

Assumptions: This was an interesting interview that differed from the others. They were quite angry throughout the interview and it appeared that the participant hadn't come to terms or accepted their FND diagnosis. It was also quite interesting to hear why the participant didn't like attending the face-to-face peer support group because other attendees were negative and complained a lot – yet, spent quite some time making negative comments throughout the interview. Although this interview hasn't give me much to think about in terms of concepts, it has given me a new appreciation of how hard the FND diagnosis is and how difficult it is to navigate.

Familiarisation: The participant was taken to hospital due to suspected stroke. They were diagnosed with FND, but they were unhappy with their diagnosis so decided to pay for a private neurology appointment (who confirmed the FND diagnosis). The participant wasn't satisfied with their private appointment as they weren't told any new information. The participant is currently not accessing treatments, but was previously seen by Occupational Therapy and Physiotherapy teams. They did not like attending the peer support group as the attendees sat their 'socialising and whinging', but 'that's not them!'.

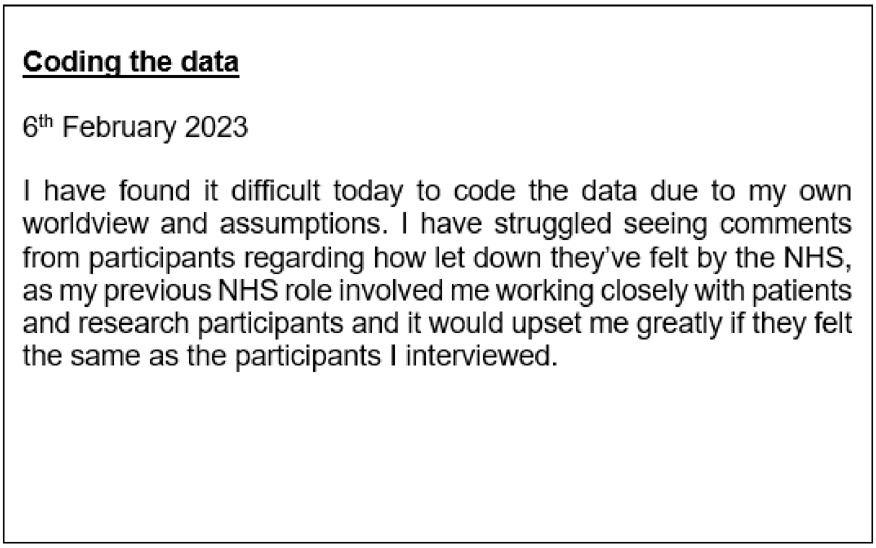
Stage 2: Coding the data

Once the familiarisation notes had been recorded, the data from each transcript were coded. There are two different types of codes: semantic and latent (Braun and Clarke, 2013). Semantic codes are more descriptive, and present the data as conveyed by the participant. Latent codes aim to pinpoint the underlying assumptions or ideologies that inform the semantic content of the dataset. Braun and Clarke (2021) recommend retaining fluidity when thinking and conceptualising codes and themes. Therefore, data were predominantly coded semantically, in order to allow the analysis to capture the participants' stated experiences and opinions. Latent coding was also utilised when suitable and relevant to the analysis.

NVivo V.12 software was used to code the data. Each transcript was coded in date order, and each data item contained in the transcripts was given equal attention. All data that appeared to be relevant or interesting to the analysis were coded. Two rounds of coding occurred. In total, 131 codes were derived from the data. Once the data in each transcript were coded, data relevant to each code were collated via NVivo V.12 to provide an overview of the common codes and ideas, which featured throughout the data.

The author reflected on their assumptions while undergoing the coding process via a reflexive diary. This included reflecting on how their worldview affected the coding and any potential barriers or challenges which may have occurred during the coding process. An excerpt from the reflexive diary can be found in Figure 9.

Figure 9: Reflexive diary entry



Coding the data

6th February 2023

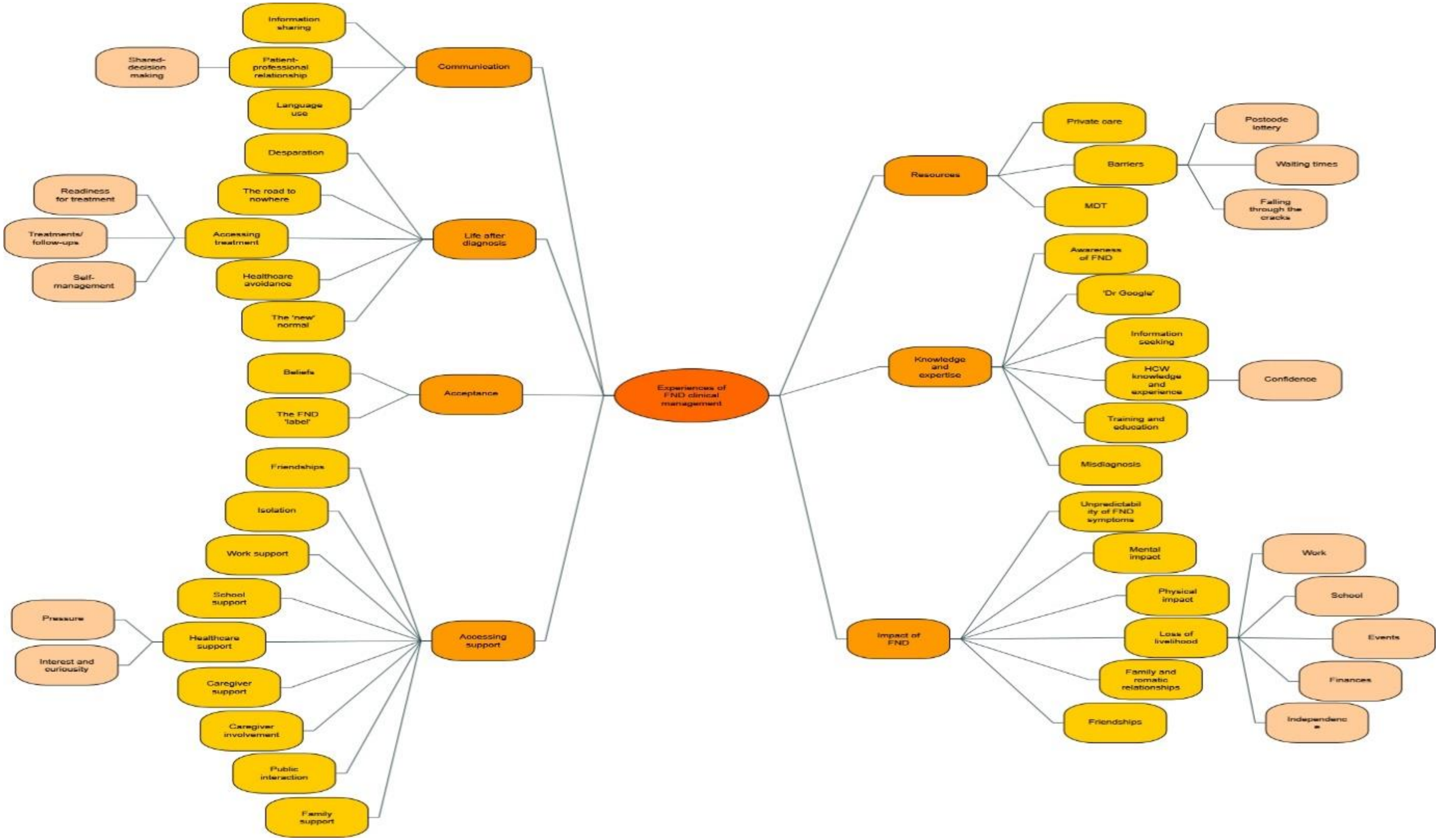
I have found it difficult today to code the data due to my own worldview and assumptions. I have struggled seeing comments from participants regarding how let down they've felt by the NHS, as my previous NHS role involved me working closely with patients and research participants and it would upset me greatly if they felt the same as the participants I interviewed.

Stage 3: Generating initial themes

Once the coding was completed, initial themes were generated. Originally, this step was referred to as 'searching for initial themes' (Braun and Clarke, 2006), however this term was updated by the authors in their latest guidance (Braun and Clarke, 2021).

The coded data were reviewed to identify potential themes or patterns in the data. Similar codes were clustered together and organised into initial themes via NVivo V.12. A thematic map was created (developed using NVivo) to display the initial themes, which is presented in Figure 10.

Figure 10: Thematic map displaying the initial interview study themes



Stage 4: Reviewing and developing themes

Once the initial themes were generated, each theme was checked against the dataset to ensure it reflected the dataset; it also had a shared meaning that was underpinned by the central concept of the work. Deviant cases (also known as outliers or negative cases) are data where a participant's viewpoint or experience does not conform to the rest of the data (Corbin and Strauss, 2014). While only a small number of deviant cases appeared, the author included the deviant cases in the analysis, as they both broaden and enhance the themes.

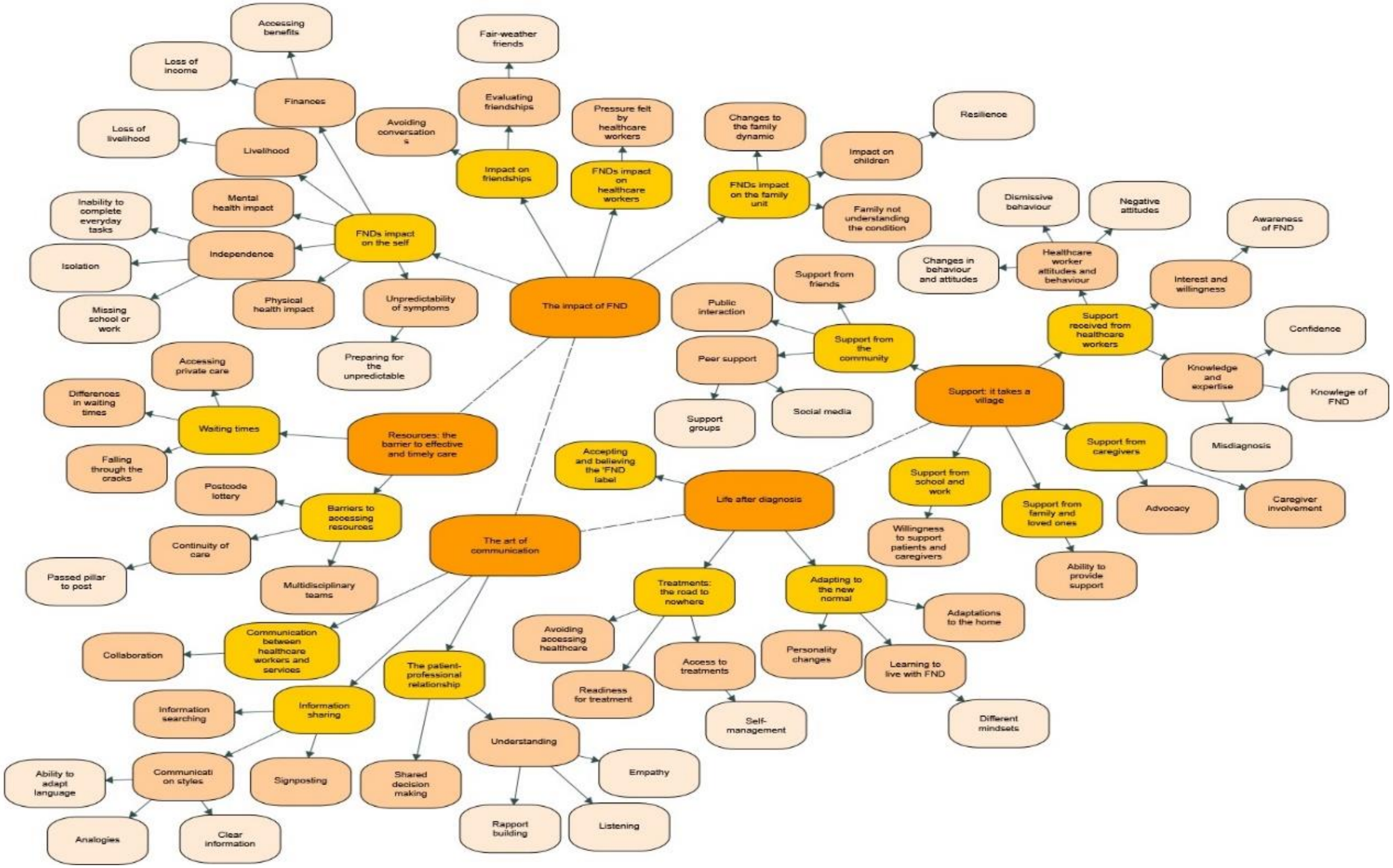
Two stages of reviewing were conducted. Firstly, the coherence of each code was reviewed in relation to the theme and sub-theme in which it was situated. If the code was not coherent to the theme/sub-theme, it was removed from the grouping. After this review, each theme was then assessed to check whether it represented the dataset in relation to the central concept of the research.

In addition, each initial theme was checked to ensure its quality. This quality check involved following the criteria set by Braun and Clarke (2012), which included reviewing:

- Whether there were enough data to support it as a theme
- Whether the data included in the theme were too diverse
- What the theme boundaries were

Initial themes, which were deemed insufficient, were removed from the finalised map (Figure 11).

Figure 11: Thematic map displaying the finalised interview study themes



Stage 5: Refining, defining and naming themes

The focus and scope of each theme was deliberated before being finalised. The focus and scope (represented in Figure 11) was compared against the data contained in each theme. If it was determined that the focus and scope were not a true reflection, the theme was refined. After the themes and sub-themes were finalised, each was given a succinct yet informative title. A description of each theme was written, which can be found in Appendix 12. The specifics of each theme were refined before stage 6.

Stage 6: Producing the report

The final stage of RTA is the production of the report. The report comprised themes, data extracts and analytic commentary. As recommended by Braun and Clarke (2021), compelling examples of the data were selected to illustrate each theme.

An important part of the report is deciding the presentation order of the final themes. Theme order should be logical, with subsequent themes building upon the previous while still presenting their own narrative (Braun and Clarke, 2012). Stepping away from the traditional presentation of research analysis in reports, Braun and Clarke (2012) recommend evidencing claims throughout the results section, rather than in the discussion. This recommendation was followed where possible. Reflections on the analytic process are described in Section 5.6.

3.2.4 Interpretation of phase one and phase two data

The data collected from phases one and two were triangulated to provide a more thorough and comprehensive understanding of the research topic (Carter et al., 2014). There are four types of triangulation (Denzin, 1970):

- Data source (utilising different data sources)
- Investigator (where two or more researchers, or investigators, are involved in the research)
- Theory (utilising two or more hypotheses or theories when researching a phenomenon)
- Methodological (utilising a variety of research methods to study a phenomenon)

The most suitable triangulation type for this work is methodological triangulation, as it involves comparing data, which have been collected on a single issue or research area using multiple methods (either run in parallel or sequentially). Methodological triangulation allows for the degree of compatibility between the multiple methods utilised to be measured (Salkind, 2010). Between-methods triangulation was used, as the approach minimises the biases of a particular methodology (e.g., only using interviews or a quantitative survey).

3.3 Reflexivity

Reflexivity is a continuous process which allows researchers to reflect on how their own assumptions, perspectives and attitudes may have influenced the research study, by questioning and reflecting on these behaviours (Cunliffe, 2003). Reflexivity allows researchers to constantly build and change their understanding, challenge the current circumstances and beliefs (Barrett et al., 2020), as well as increase the research study's rigour and trustworthiness (Davis, 2020).

Throughout each stage of this thesis, reflexivity was engaged in a variety of ways. A notepad was used to jot notes about the author's thoughts and any participant comments of interest. In addition, reflection took place as soon as possible after each interview. Lastly, the researcher immersed herself in the reflexivity process, by answering self-reflexive and reflexive questions about the study's participants and the audience listed by Patton (2015).

These questions included:

- *"What do I know?*
- *How do I know what I know?*
- *What shapes and has shaped my perspective?*
- *How have my perceptions and my background affected the data I have collected and my analysis of those data?*
- *How do those studied know what they know?*
- *How do those who receive my findings make sense of what I give them?"*

(Patton, 2015, p.604-605)

3.3.1 Author reflexivity

The author of this thesis is a white, working-class female university student, based in North Yorkshire. Through her own personal and professional background, she indirectly identified with the three population groups included in this work. While not being a trained clinician, she worked in a variety of clinical and non-clinical mental health roles in the NHS for eight years before she commenced this doctoral research and delivered clinical assessments to patients and research participants. In addition, before starting the interview study, she shadowed a neurologist in their clinic to gain a better understanding of how FND is diagnosed in the NHS. The author suffers from migraines (an unexplained illness) and was also an informal caregiver for a family member diagnosed with a rare condition (motor neurone disease), where she attended medical appointments, advocated for them when they could not speak for themselves, and provided home care.

While having previous experience of conducting qualitative work, the author completed a qualitative research methods module (at masters degree level) to fully prepare for the qualitative elements of this thesis. The author discussed each part of this work and reflected on the research process and its findings with three academic supervisors (two female and one male), all of whom are members of staff employed by the University of York. The supervisors brought a wealth of methodological and clinical expertise to this research.

This thesis represents the experiences and perspectives of UK-based FND patients, caregivers and NHS healthcare workers. Patient and public involvement (PPI) members were also UK-based and had lived experiences or expertise of FND. There were five PPI members in total; three female and two male. Three were diagnosed with FND and two were caregivers. Two PPI members (both patients with an FND diagnosis) were previously known to the author via a research study. The remaining three became involved as they contacted the author (via social media) to share their views on FND and were subsequently invited by the author to share their perspectives on the conducted research as part of this thesis). All had experiences of accessing NHS services. Further information on the PPI members can be found in Appendix 13. PPI members provided advice and feedback on participant-facing documents (such as topic guides and survey questions).

3.4 Data Protection

All data and datasets were stored in a secure, password-protected and encrypted computer database at the University of York. All participants were given a unique participant code. Any identifiable data (referring to the contact details provided at will from the survey participants who wished to take part in the interview study) were stored on a separate secure database, with only the author and supervisors having access to the data. Data were stored as per University of York policy.

3.5 Patient and public involvement

Patient and public involvement (PPI) representatives (including patients, caregivers and healthcare workers) were included in the research. In Stage 1, PPI representatives were contacted via email to provide any relevant information for the review, via the consultation exercise. Patients, caregivers and members of relevant organisations (such as the FND Society) were asked to provide any evidence which may be of relevance for the review. In addition, the consultation exercise was advertised on social media inviting patients, caregivers and healthcare workers to provide relevant information. In stage 2, PPI representatives were involved in the development and subsequent amendments of the surveys and topic guides, checking the findings for accuracy and dissemination of the study results. For accessibility reasons, the PPI representatives were asked how they would like to receive the texts before they read through the chapter and manuscript, and provided comments. The text was presented to the PPI representatives in Ariel font type, size 12. PPI representatives (patients and caregivers) piloted the survey, and then advised on changes and amendments to the survey questions.

3.6 Ethics Approval

Ethical approval from the University of York ethics committee was sought before proceeding with the survey and interview studies. Ethical approval for the survey was granted on 18th December 2020 (reference number: HSRGC/2020/391/B) and on 13th May 2022 for the interview study (reference number: HSRGC/2022/508/H) Comments and advice from the ethics committee were incorporated. The ethical approval documents can be found in Appendix 8. As no research data was collected during the scoping review's consultation exercise, ethical approval was not needed.

3.7 Ethical considerations

There were a number of ethical considerations concerning this thesis. Throughout all aspects of this research, the author aimed to make study participation a positive experience for all involved. Participants were given opportunities to discuss their experiences at length, and each individual study was developed to ensure that they were accessible. The topic guides used in the interviews and the bespoke survey questions were piloted, in order to determine completion duration and see if they were easy to understand. To minimise participant burden, survey and interview questions were kept to a minimum. In addition, participants were given the option to take up to two weeks when completing the survey to reduce the chance of fatigue.

There was a small risk of eye strain, due to looking at a computer screen for a long period of time. However, this was not deemed to be a significant issue, as the survey was designed to take no longer than 20 minutes to complete. If a participant selected to use videoconferencing (e.g., Zoom) for the interview study, they were offered opportunities to take a break if they were struggling to look at the computer screen.

Prospective participants were provided with study information (via a participant information sheet; Appendix 14) well in advance of study participation (at least 24 hours); this ensured they had sufficient time to fully understand their role in the research. In addition, all participants were required to provide informed consent (Appendix 15) prior to survey or interview participation.

To address any potential power imbalance between the researcher and participant, participants were provided with information regarding the nature of the study and how their information would be used. Furthermore, participants were given opportunities to ask questions. To reduce the risk of a power imbalance, interviews were conducted with only the participant and interviewer present, and took place in a suitable setting for the participant.

This research explored a sensitive subject, and had the potential to cause some distress or powerful and challenging emotions for participants. Before commencing the survey or interview, participants were reminded that they may find the questions emotive, that they could withdraw from the research (without needing to provide a reason for withdrawal) and they would be able to take breaks if needed. Participants were not compelled to answer any questions in the survey or interviews; if they wished to not answer a survey question, they had the option to tick ‘prefer not to answer’ or could leave the question unanswered. They could also not give a response during their interview. If a participant become emotional or upset during the interview study, the researcher asked the participant if they would like to pause or end the interview. After each interview, the interviewer debriefed the participant to ensure they were not distressed and, if needed, signposted to relevant services or organisations listed in the participant information sheet (Appendix 14). It was planned that if any information provided would require disclosure (such as professional misconduct or neglect), or patients displayed any worrying signs of serious distress, the supervisors would be informed as soon as possible to advise on how best to proceed.

All participants were given a unique identification number; this number was used on study documents and no identifiable information was presented in the findings, or in any subsequent publications. In addition, pseudonyms (e.g., HCW1, PT1022 etc.) were given to participants during the research analysis. Any identifiable information provided was removed from the data to ensure confidentiality.

Lastly, the interviews were recorded via Zoom. Audio files, transcripts and electronic consent forms were stored on a secure, encrypted computer at the University of York. If hard copies of consent forms were completed, it was planned that they would be stored securely in a locked filing cabinet at the University of York. Only the author and supervisors had access to the study documents.

3.8 COVID-19 considerations

The global COVID-19 pandemic has caused disruptions to research activities on an unprecedented scale. This research idea was developed prior to the pandemic, and measures were put in place to ensure the safety of both participants and the author.

Ideally, all parts of this thesis involving recruitment would have been conducted in person, and where possible, in a setting suitable for the participant. This was to enable the individual to be comfortable and allow a rapport to be built. Face-to-face interviews also ensure the interviewer can monitor the participant’s demeanour and potential distress via changes in their non-verbal communication (e.g., body language and facial expressions), and then take appropriate action (e.g., pausing or ending the interview). However, due to the COVID-19 pandemic government and University restrictions, the methods in which to conduct the research were amended. The survey study was redesigned to be completed online (with the option of a paper copy being sent out to participants to complete), with interviews to be held via videoconference (e.g., Zoom), which allowed the participant and interviewer to be face-to-face virtually. If the participant had limited or no internet access, the interview was held over the telephone. University of York data protection guidelines were followed to ensure video and telephone calls were held securely. It was planned that if any interviews were held in a face-to-face setting, social distancing guidelines would be followed.

Chapter 4: An online survey exploring the clinical management of Functional Neurological Disorder (FND) in the UK

The following chapter presents the findings of the mixed-methods survey conducted as part of this thesis.

The survey was administered between 24th November 2021 and the 28th March 2022, and aimed to explore the experiences and perspectives of UK-based patients, caregivers and healthcare workers on the diagnostic and treatment processes for functional neurological disorder (FND). In addition, the survey aimed to collect information on the diagnostic tests and treatments currently being utilised by UK health services.

Although a lower than anticipated number of caregivers (n = 34) and healthcare workers (n = 28) completed the survey, a high number of patients (n = 257) responded. This chapter begins by presenting the demographic data for all three population groups. Socioeconomic data (e.g., qualifications, access to benefits and working and living situation) will then be examined. This will be followed by a detailed narrative account (Popay et al., 2006) of the information provided by each population group. Respondents were asked questions relevant to their population group. Where possible, the data from all population groups are presented together. A content analysis (Krippendorff, 1980) has been conducted on the text answers given by the survey respondents.

The survey results have been compared to the findings from the scoping review (see Chapter 2) and recommendations for the clinical management of FND are suggested.

The methods utilised for this survey are presented in Chapter 3.

4.1 Rationale for Survey

As discussed in Chapter 2, the clinical management of FND can be challenging for both healthcare workers and patients, due to the limited laboratory based-diagnostic tests and interventions available. Further, there is a lack of clinical guidance available for healthcare workers to follow when clinically managing FND, and there is no official NICE guidance. This indicates that the clinical management of FND in UK health services may vary. This lack of guidance may impact on the shared decision-making process between patients and healthcare workers who may be unaware of specific diagnostic pathways or treatments. Therefore, research investigating the diagnostic tools and treatments used in the UK is needed to establish both how FND patients are being assessed and treated, and see whether the variety of tools and treatments being used across services and NHS Trusts have a different impact on the patient experience.

A small handful of studies have documented the experiences and perspectives of healthcare workers on FND and its clinical management, however there is very limited evidence relating to patients and their caregivers experiencing it. Furthermore, the few studies (such as Kanaan et al., 2011, O'Connell, 2017, and Rawlings et al., 2017) exploring this phenomenon only recruited a small sample size or focused on one setting (e.g., accident and emergency). Thus, research is needed to explore the experiences (both positive and negative) of healthcare workers, patients and caregivers involved in the diagnosis, treatment, and care of FND.

4.2 Aims & Objectives

This survey aimed to explore the experiences of healthcare workers, patients and caregivers on the diagnostic and treatment processes for FND.

The objectives of the survey were to:

- Record the experiences of patients, healthcare workers and caregivers on the diagnosis and treatment of FND
- Identify the tools and instruments used during the FND diagnostic process
- Identify the treatments used to support a patient with FND
- Identify patient needs during the diagnostic and treatment process for FND
- Identify information to be included in the subsequent qualitative interview topic guide

4.3 Results

In total, 319 participants completed the survey. Participants were recruited using opportunistic sampling via organisations and charities (listed in Table 6), and research study specific mailing lists made available to the author from a member of the PhD supervisory team (CFC).

As reported in Chapter 3, a sample size of 105 (with 35 participants being recruited to each group) was planned, as this would allow for a range of experiences and perspectives to be analysed and reported in this chapter. Whilst this target was met for the patient group, it was narrowly missed for the caregiver (n = 34) and healthcare worker (n = 28) groups. These lower than anticipated recruitment figures may have been due to strain caused by the COVID-19 pandemic. It has been reported that the pandemic caused healthcare workers to face immense challenges, having to work long hours to manage an increase in hospital admissions with fewer staff available, and increased feelings of stress and burden (British Medical Association, 2022). Therefore, this increase in stress and working hours may have led to fewer healthcare workers being able to complete this survey. It has also been suggested that caregivers are less likely than other population groups to participate in research due to burden or a lack of available time (Malm et al., 2021). In contrast, the patient population group is well above the anticipated recruitment figure (n = 257). This is due to several charity organisations and social media pages sharing information regarding the study, leading to many of their followers completing the survey.

The survey results for each population group have been collated where possible.

4.3.1 Demographic data

All participants (n = 319) were asked demographic questions. 83.1% of participants (n = 265) identified as female and 15% (n = 48) as male. The remaining 1.9% of participants identified as non-binary (n = 4) or preferred not to answer the question (n = 2). As age brackets were used, a specific age range cannot be reported. The age group with the most participants was 45-54 years (30.7%; n = 98). Most participants stated their ethnicity as white British (81.8%; n = 261) or white-any other white background (6.6%; n = 21). Lastly, the majority of participants lived in England (64.6%; n = 206) or Scotland (24.6%; n = 79).

Table 13 (below) provides a detailed breakdown of the demographic information.

Table 13: Demographic information

	Patient group (n = 257)	**Caregiver group (n = 34)**	**Healthcare worker group (n = 28)**	**Total (n = 319)**
Gender	Female = 220 (85.6%) Male = 33 (12.8%) Non-binary = 4 (1.6%)	Female = 29 (85.3%) Male = 5 (14.7%)	Female = 16 (57.1%) Male = 10 (35.7%) Prefer not to say = 2 (7.1%)	Female = 265 (83.1%) Male = 48 (15%) Non-binary = 4 (1.3%) Prefer not to answer = 2 (0.6%)
Age range	18-24 = 23 (8.9%) 25-34 = 50 (19.5%) 35-44 = 53 (20.6%) 45-54 = 71 (27.6%) 55-64 = 50 (19.5%) 65-74 = 9 (3.5%) 85+ = 1 (0.4%)	35-44 = 7 (20.6%) 45-54 = 18 (52.9%) 55-64 = 7 (20.6%) 65-74 = 2 (5.9%)	25-34 = 5 (17.9%) 35-44 = 10 (35.7%) 45-54 = 9 (32.1%) 55-64 = 3 (10.7%) Prefer not to say = 1 (3.6%)	18-24 = 23 (7.2%) 25-34 = 55 (17.2%) 35-44 = 70 (21.9%) 45-54 = 98 (30.7%) 55-64 = 60 (18.8%) 65-74 = 11 (3.4%) 75-84 = 0 (0%) 85+ = 1 (0.3%) Prefer not to answer = 1 (0.3%)
Ethnicity	White British = 213 (82.9%) White - any other white background = 16 (6.2%) Irish = 3 (1.2%) Caribbean = 1 (0.4%)	White British = 28 (82.4%) White - any other white background = 2 (5.9% Prefer not to say = 1 (2.9%) Missing = 3 (8.8%)	White British = 20 (71.4%) White - any other white background = 3 (10.7%) Indian = 1 (3.6%) Irish = 1 (3.6%)	White British = 261 (81.8%) White - any other white background = 21 (6.6%) Irish = 4 (1.3%) Caribbean = 1 (0.3%)

	Patient group (n = 257)	**Caregiver group (n = 34)**	**Healthcare worker group (n = 28)**	**Total (n = 319)**
	White and Asian = 1 (0.4%) African = 2 (0.8%) Prefer not to say = 1 (0.4%) Missing = 20 (7.8%)		White and Asian = 1 (3.6%) Prefer not to say = 1 (3.6%) Missing = 1 (3.6%)	Indian = 1 (0.3%) White and Asian = 2 (0.6%) African = 2 (0.6%) Prefer not to say = 3 (0.9%) Missing = 24 (7.5%)
Geographical area	*England (n = 162)* South East = 33 (12.8%) Yorkshire and the Humber = 26 (10.1%) North West = 21 (8.2%) South West = 21 (8.2%) East Midlands = 14 (5.4%) East of England = 14 (5.4%) West Midlands = 12 (4.7%) North East = 11 (4.3%) London = 10 (3.9%) *Scotland (n = 69)* Central= 21 (8.2%) Grampian = 21 (8.2%)	*England (n = 23)* South East = 7 (20.6%) East Midlands = 6 (17.6%) North East = 4 (11.8%) Yorkshire and the Humber = 2 (5.9%) London = 1 (2.9%) North West = 1 (2.9%) South West = 1 (2.9%) West Midlands = 1 (2.9%) *Scotland (n = 7)* Central = 2 (5.9%) Grampian = 2 (5.9%) Borders = 1 (2.9%)	*England (n = 21)* North East = 7 (25%) London = 5 (17.9%) South East = 3 (10.7%) Yorkshire and the Humber = 2 (7.1%) East of England = 1 (3.6%) North West = 1 (3.6%) South West = 1 (3.6%) West Midlands = 1 (3.6%) *Scotland (n = 3)* Lothian = 2 (7.1%) Grampian = 1 (3.6%)	*England (n = 206)* South East = 43 (13.5%) Yorkshire and the Humber = 30 (9.4%) North West = 23 (7.2%) South West = 23 (7.2%) North East = 22 (6.9%) East Midlands = 20 (6.3%) London = 16 (5%) East of England = 15 (4.7%) West Midlands = 14 (4.4%) *Scotland (n = 79)* Grampian = 24 (7.7%) Central = 23 (7.2%)

	Patient group (n = 257)	**Caregiver group (n = 34)**	**Healthcare worker group (n = 28)**	**Total (n = 319)**
	Highlands and Islands = 7 (2.7%) Lothian = 7 (2.7%) Strathclyde = 7 (2.7%) Borders = 3 (1.2%) Dumfries and Galloway = 3 (1.2%) *Wales (n = 13)* South Wales = 9 (3.5%) North Wales = 3 (1.2%) Mid-Wales = 1 (0.4%) *Ireland (n = 5)* Antrim = 2 (0.8%) Down 2 (0.8%) Londonderry = 1 (0.4%) Missing = 8 (3.1%)	Dumfries and Galloway = 1 (2.9%) Lothian = 1 (2.9%) *Wales (n = 3)* North Wales = 2 (5.9%) South Wales = 1 (2.9%) Missing = 1 (2.9%)	*Wales (n = 2)* South Wales = 2 (7.1%) *Ireland (n = 1)* Antrim = 1 (3.6%) Missing = 1 (3.6%)	Lothian = 10 (3.1%) Highlands and Islands = 7 (2.2%) Strathclyde = 7 (2.2%) Borders = 4 (1.3%) Dumfries and Galloway = 4 (1.3%) *Wales (n = 18)* South Wales = 12 (3.8%) North Wales = 5 (1.6%) Mid-Wales = 1 (0.3%) *Ireland (n = 6)* Antrim = 3 (0.9%) Down = 2 (0.6%) Londonderry = 1 (0.3%) Missing = 10 (3.13%)

4.3.2 Geographic and socioeconomic data

Socioeconomic data were collected from both patient and caregiver respondents. This was to explore the potential links between symptom severity/type, experiences and socioeconomic class.

Respondents were asked about housing and residence, area type, income types, job title (if applicable), work status and hours worked. These data were used to establish each respondent’s National Statistics Socio-Economic Class (NS-SEC; Office for National Statistics, 2022).

Firstly, respondents were asked whether they own or rent their current residence. For both patients and caregivers, the majority owned their own property (n = 126 and n = 26, respectively). 86 patients and 4 caregivers stated they rented their residence (either privately rented or were renting from their local council), with the remaining stating they lived with family members or in a housing association home. Survey respondents were also asked if they live alone or with others. The majority of patients (n = 121; 47.1%) lived with their spouse or partner, whereas the majority of caregivers lived with their family (n = 19, 55.9%). Tables 14 and 15 provide a detailed breakdown of these figures.

Table 14: Do you own or rent your current residence?

	Patient (n = 257)	**Caregiver (n = 34)**
Own	126 (49.2%)	26 (76.5%)
Privately rent	43 (16.7%)	4 (11.8%)
Council rent	43 (16.7%)	0
Live at home/with family members	27 (10.5%)	1 (2.9%)
Housing association	8 (3.1%)	1 (2.9%)
Other	6 (2.3%)	0
Missing	4 (1.5%)	2 (5.9%)

Table 15: Who do you live with?

	Patient (n = 257)	**Caregiver (n = 34)**
I live with my spouse/partner	121 (47.1%)	14 (41.2%)
I live with family	95 (37%)	19 (55.9%)
I live alone	47 (18.3%)	2 (5.9%)
Other	11 (4.3%)	0
I live in a residential association	1 (0.4%)	0
Missing	1 (0.4%)	2 (5.95)

Participants were able to select more than one option.

Following this question, respondents were asked to select if their residence was situated in an urban, suburban or rural area. Most patients (n = 111; 43.2%) and caregivers (n = 15; 44.1%) stated they lived in a suburban area. 87 patients (33.9%) and 10 caregivers (29.4%) lived in a rural area, while 55 patients (21.4%) and 5 caregivers (14.7%) lived in an urban area.

Patient respondents were asked to report whether they were accessing state benefits. Although there is a wide range of benefits available for FND (such as personal independence payment (PIP) or universal credit), only a minority reported accessing benefits, with 44 (17.1%) receiving child benefits, 56 (21.8%) receiving universal credit, 11 (4.3%) receiving income support, 10 (3.9%) receiving tax credits and 79 (30.7%) accessing other state benefits.

All respondents were asked what formal qualifications they have achieved. Just over half of patients (n = 141; 54.9%) and caregivers (n = 19; 55.9%) and almost all healthcare workers (n = 27; 96.4%) had completed a university degree. Patients and caregivers were most likely to have achieved at least one GCSE (or equivalent) qualification (80.9% and 91.2%, respectively). 3.1% of patients and 2.9% of caregivers had no qualifications.

When asked about work status, only 39.3% (n = 101) of patients and 44.1% (n = 15) of caregivers reported that they were in employment, differing from the 96.4% (n = 27) of healthcare workers. 107 patients (41.6%) stated they were temporarily away from work due to illness, were unable to work due to illness or were disabled and unable to work. Only one caregiver (2.9%) reported being unable to work due to illness.

All respondents were asked to report their job title and hours worked per week in their main job. The job titles were used to calculate the NS-SEC analytic class, which is reported in Table 16. A variety of working hours were reported, with most participants working 31-48 hours per week (patients: n = 104; 40.5%, caregivers: n = 14; 41.2%, healthcare workers: n = 19; 67.9%).

The data provided in this section were used to calculate each respondent’s NS-SEC analytic class (reported in Table 16). Almost all healthcare workers (n = 27; 94.6%) were placed into group 1 analytic class (higher managerial, admin and professional occupations) and only one placed in the intermediate occupations (group 3) analytic group. This differed for patients and caregivers, with most (26.5% and 35.3%, respectively) being placed in the lower professional and higher technical occupations group (group 2). Patients were also more likely to be placed in analytic groups 6 (semi-routine occupations, 19.1%) or 8 (never worked, students, and long-term unemployed, 12.8%).

Table 16: NS-SEC analytic class

	Patient (n = 257)	**Caregiver (n = 34)**	**Healthcare worker (n = 28)**
Higher managerial, admin and professional occupations (group 1)	28 (10.9%)	7 (20.6%)	27 (96.4%)
Lower professional and higher technical occupations (group 2)	68 (26.5%)	12 (35.3%)	0
Intermediate occupations (group 3)	45 (17.5%)	7 (20.6%)	1 (3.6%)
Small employers and own account workers (group 4)	7 (2.7%)	0	0
Lower supervisory and technical occupations (group 5)	3 (1.2%)	0	0
Semi-routine occupations (group 6)	49 (19.1%)	4 (11.8%)	0
Routine occupations (group 7)	9 (3.5%)	1 (2.9%)	0
Never worked, students, and long-term unemployed (group 8)	33 (12.8%)	0	0
Missing	15 (5.8%)	3 (8.8%)	0

Analytic groups with more than 10% of the total patient population (groups 1, 2, 3, 6, 8) were compared to explore the differences between symptoms, time to diagnosis and reported experiences. A one-way ANOVA was conducted to compare the effect of NS-SEC analytic class and the amount of symptoms presented, revealing a statistically significant difference between mean symptom amount between the groups (F(4, 217) =

3.42, p = 0.010). A post-hoc Tukey test revealed no significant differences between any of the groups (p < 0.05).

The average amount of symptoms reported increased from patients in higher managerial and professional occupations (group 1) up to group 6 (semi-routine occupations). The average number of reported symptoms was 8.32 (SD = 3.65) for group 1, 9.13 (SD = 3.72) for group 2, 10.1 for group 3 (SD = 4.05) and 10.7 (SD = 4.04) for group 6. Interestingly, the lowest average of reported symptoms was group 8 (students and long-term unemployed), with 8.18 symptoms (SD = 3.99).

Regarding the duration of time from first reporting symptoms to diagnosis, no major differences were found between groups for those diagnosed between 0 months and 5 years. However, it took over 5 years to diagnose a large percentage of those in groups 1 (n = 9; 32.1%), and 6 (n = 11; 22.4%).

A small difference was found when comparing if patient respondents agreed with their FND diagnosis. Participants in groups 1, 6 and 8 were more likely to agree with their diagnosis (89.3%, 85.7%, and 84.8%, respectively) than patients in groups 2 and 3 (64.7% and 62.2%, respectively).

Interestingly, the majority of group 1 patients stated that healthcare workers were supportive of them and their condition (n = 15, 53.6%), whereas more patients in groups 2, 3 and 6 felt that healthcare workers were not supportive (54.4%, 35.3% and 34.7%, respectively). Patients in group 8 were almost evenly split in stating whether they felt that they were supportive (‘yes’: n = 15; 45.5%, ‘no’: n = 14; 42.4%) Finally, most patients in all reported groups stated that services could have done things differently during the diagnostic process.

Table 17 reports the findings from each NS-SEC analytic group.

Table 17: NS-SEC data comparison

	Average amount of symptoms reported (range)	Time to diagnosis	Do you agree with your diagnosis?	Were healthcare workers supportive of you and your condition?	Is there anything services should have done differently during the diagnostic process?
Higher managerial, admin and professional occupations (group 1) (n = 28)	8.32 (2-17)	0-6 months = 10 (35.7%) 6-12 months = 6 (21.4%) 1-2 years = 0 2-5 years = 3 (10.7%) 5+ years = 9 (32.1%)	Yes = 25 (89.3%) No = 2 (7.1%) Missing = 1 (3.6%)	Yes = 15 (53.6%) No = 9 (32.1%) Prefer not to answer = 1 (3.6%) Missing = 3 (10.7%)	Yes = 17 (60.7%) No = 9 (32.1%) Prefer not to answer = 1 (3.6%) Missing = 1 (3.6%)
Lower professional and higher technical occupations (group 2) (n = 68)	9.13 (1-16)	0-6 months = 28 (41.2%) 6-12 months = 7 (10.3%) 1-2 years = 13 (19.1%) 2-5 years = 8 (11.8%) 5+ years = 6 (8.9%) Don’t know = 1 (1.5%) Missing = 5 (7.4%)	Yes = 44 (64.7%) No = 17 (25%) Prefer not to say = 2 (2.9%) Missing = 5 (7.4%)	Yes = 24 (35.3%) No = 37 (54.4%) Prefer not to answer = 1 (1.5%) Missing = 6 (8.8%)	Yes = 35 (51.5%) No = 22 (32.4%) Prefer not to answer = 4 (5.9%) Missing = 7 (10.3%)
Intermediate occupations (group 3) (n = 45)	10.1 (0-17)	0-6 months = 10 (22.2%) 6-12 months = 9 (20%) 1-2 years = 4 (8.9%) 2-5 years = 9 (20%)	Yes = 28 (62.2%) No = 9 (20%)	Yes = 17 (35.3%) No = 21 (46.7%) Missing = 6 (13.3%)	Yes = 24 (53.3%) No = 9 (20%) Prefer not to answer = 2 (4.4%)

	Average amount of symptoms reported (range)	**Time to diagnosis**	**Do you agree with your diagnosis?**	**Were healthcare workers supportive of you and your condition?**	**Is there anything services should have done differently during the diagnostic process?**
		5+ years = 6 (13.3%) Don't know = 2 (4.4%) Missing = 5 (11.1%)	Prefer not to say = 1 (2.2%) Missing = 6 (13.3%)		Missing = 10 (22.2%)
Small employers and own account workers (group 4) (n = 7)	12 (8-18)	0-6 months = 3 (42.9%) 1-2 years = 1 (14.3%) 2-5 years = 1 (14.3%) 5+ years = 1 (14.3%) Missing = 1 (14.3%)	Yes = 4 (57.1%) No = 1 (14.3%) Prefer not to say = 1 (14.3%) Missing = 1 (14.3%)	Yes = 2 (28.6%) No = 4 (57.1%) Missing = 1 (14.3%)	Yes = 5 (71.4%) No = 1 (14.3%) Prefer not to say = 1 (14.3%)
Lower supervisory and technical occupations (group 5) (n = 3)	11.7 (11-12)	6-12 months = 1 (33.3%) 1-2 years = 1 (33.3%) 2-5 years = 1 (33.3%)	Yes = 1 (33.3%) No = 1 (33.3%) Missing = 1 (33.3%)	Yes = 2 (66.7%) No = 1 (33.3%)	No = 2 (66.7%) Missing = 1 (33.3%)
Semi-routine occupations (group 6)	10.7 (2-17)	0-6 months = 21 (42.9%) 6-12 months = 5 (10.2%) 1-2 years = 3 (6.1%)	Yes = 42 (85.7%) No = 4 (8.2%)	Yes = 17 (34.7%) No = 21 (42.9%)	Yes = 31 (63.3%) No = 12 (24.5%)

	Average amount of symptoms reported (range)	**Time to diagnosis**	**Do you agree with your diagnosis?**	**Were healthcare workers supportive of you and your condition?**	**Is there anything services should have done differently during the diagnostic process?**
(n = 49)		2-5 years = 7 (14.3%) 5+ years = 11 (22.4%) Missing = 2 (4.1%)	Missing = 3 (6.1%)	Prefer not to say = 2 (4.1%) Missing = 9 (18.4%)	Prefer not to say = 2 (4.1%) Missing = 4 (8.2%)
Routine occupations (group 7) (n = 9)	12.9 (7-18)	6-12 months = 3 (33.3%) 1-2 years = 3 (33.3%) 2-5 years = 3 (33.3%)	Yes = 9 (100%)	Yes = 6 (66.7%) No = 2 (22.2%) Prefer not to say = 1 (11.1%)	Yes = 4 (44.4%) No = 4 (44.4%) Prefer not to say = 1 (11.1%)
Never worked, students, and long-term unemployed (group 8) (n = 33)	8.2 (1-16)	0-6 months = 15 (45.5%) 6-12 months = 4 (12.1%) 1-2 years = 2 (6.1%) 2-5 years = 4 (12.1%) 5+ years = 5 (15.2%) Don’t know = 1 (3%) Missing = 2 (6.1%)	Yes = 28 (84.8%) No = 2 (6.1%) Prefer not to say = 2 (3%) Missing = 2 (6.1%)	Yes = 15 (45.5%) No = 14 (42.4%) Missing = 4 (12.1%)	Yes = 21 (63.6%) No = 10 (30.3%) Missing = 2 (6.1%)

4.3.3 Service mapping

One of the objectives of this survey was to map the current FND diagnostic tests and treatments being used in UK health services. All participants were asked to report the tests and treatments that were used to diagnose and treat FND patients (patient and caregiver respondents) or the tests and/or treatments used in their service (healthcare worker respondents).

Diagnostic tools and treatment data were reported by 309 participants located in 22 UK regions. Of these, six regions had under five participants reporting information (Antrim, Borders, Down, Dumfries and Galloway, Londonderry and Mid-Wales), therefore have not been included in the service mapping due to lack of data. The main types of diagnostic tests reported across all regions include neurological exams, blood tests and MRI scans, while the main treatments reported include CBT, medication and physiotherapy. Table 18 details the most commonly reported diagnostic tools and treatments for each region.

Table 18: Diagnostic tools and treatments used across the UK

Region	N	Diagnostic tools	Treatments
England			
South East	43	Neurological exam (n = 26) MRI scan (n = 21) Blood test (n = 20)	Physiotherapy (n = 17) Medication (n = 15) CBT (n = 7)
Yorkshire and the Humber	30	MRI scan (n = 19) Neurological exam (n = 17) Blood test (n = 15)	Medication (n = 10) Occupational therapy (n = 7) Psychotherapy (n = 7)
South West	23	MRI scan (n = 15) Neurological exam (n = 11) Blood test (n = 10)	Occupational therapy (n = 8) Physiotherapy (n = 8) Mindfulness-based therapy (n = 6)
North West	23	Neurological exam (n = 15) MRI scan (n = 12) Blood test (n = 11)	CBT (n = 7) Physiotherapy (n = 6) Educational website (n = 4) Medication (n = 4)
North East	22	MRI scan (n = 11) Neurological exam (n = 11) CT scan (n = 9) Eye-witness reports (n = 9)	CBT (n = 9) Physiotherapy (n = 9) Medication (n = 8)
East Midlands	20	Neurological Exam (n = 11)	Physiotherapy (n = 5)

Region	N	Diagnostic tools	Treatments
		Blood test (n = 8) MRI scan (n = 7)	CBT (n = 4) Medication (n = 4) Occupational therapy (n = 4)
London	17	MRI scan (n = 9) Neurological exam (n = 9) EEG test (n = 8)	Medication (n = 8) CBT (n = 5) Occupational therapy (n = 5) Physiotherapy (n = 5)
East of England	14	Blood test (n = 10) Neurological exam (n = 8) MRI scan (n = 8)	CBT (n = 4) Medication (n = 4) Occupational therapy (n = 4)
West Midlands	14	MRI scan (n = 9) Neurological exam (n = 8) Positive signs (n = 7)	Physiotherapy (n = 5) Medication (n = 4) CBT (n = 3)
Scotland			
Grampian	24	Neurological exam (n = 16) Blood test (n = 15) MRI scan (n = 9) Positive signs (n = 9)	Medication (n = 7) Physiotherapy (n = 6) Mindfulness-based therapy (n = 3)
Central	23	Neurological exam (n = 18) Blood test (n = 15) MRI scan (n = 12)	Medication (n = 9) Physiotherapy (n = 8) Educational Website (n = 3)
Lothian	10	Neurological exam (n = 6) Positive Signs (n = 6) Blood test (n = 3) EEG test (n = 3) Eye-witness reports (n = 3)	Physiotherapy (n = 3) CBT (n = 2)
Highlands and Islands	7	MRI scan (n = 5) Neurological exam (n = 5) Blood test (n = 4)	Medication (n = 4) CBT (n = 2) Mindfulness-based therapy (n = 2) Physiotherapy (n = 2)
Strathclyde	7	Neurological exam (n = 5) MRI scan (n = 4) Blood test (n = 3)	Medication (n = 4) Physiotherapy (n = 4) CBT (n = 2)
Wales			

Region	N	Diagnostic tools	Treatments
South Wales	12	MRI scan (n = 8) Neurological exam (n = 8) Blood test (n = 7)	Medication (n = 7) CBT (n = 4) Physiotherapy (n = 4)
North Wales	5	Blood test (n = 4) Neurological exam (n = 3) CT scan (n = 2) EEG test (n = 2) EMG test (n = 2) MRI scan (n = 2)	CBT (n = 2)

Breaking these figures down further, Figures 12 and 13 show the frequency in which the main diagnostic tests and treatments are used in each region. Neurological exams have not been included in Figure 12 as the examinations used may vary between regions.

Figure 12: Frequency of the main diagnostic tests used in services across the UK

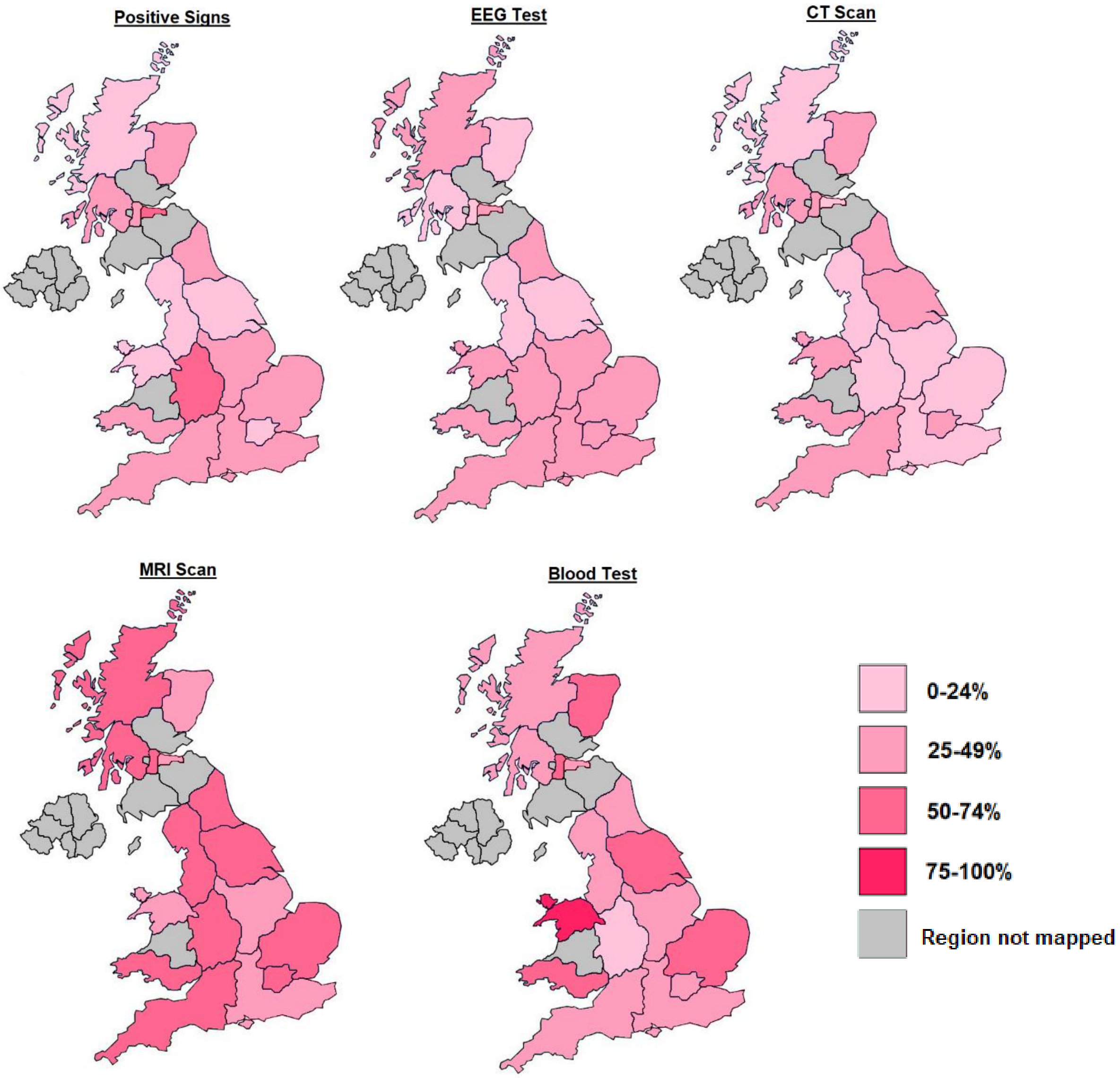
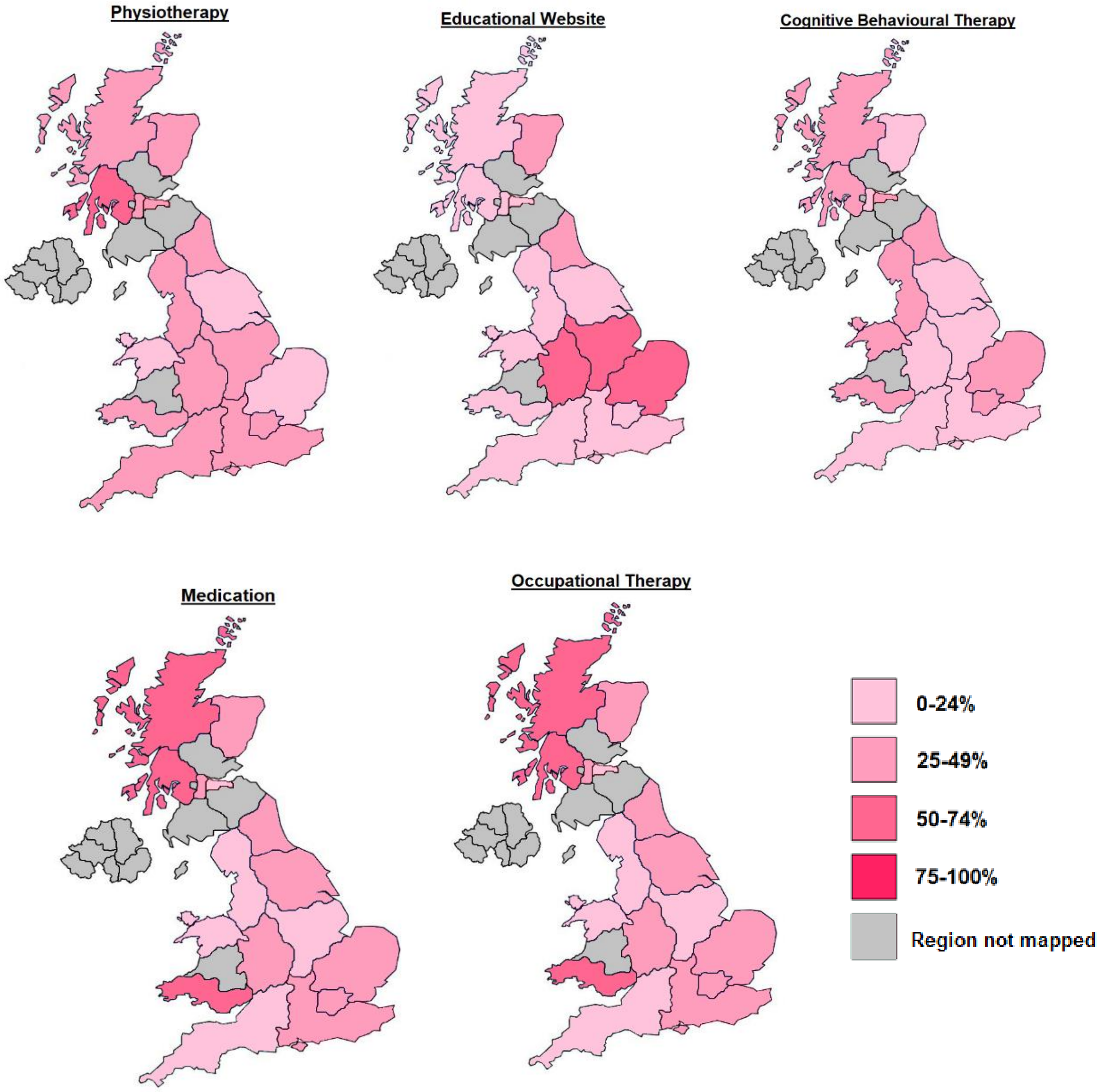


Figure 13: Frequency of the main treatments used by services across the UK



To strengthen the service mapping, a freedom of information (FOI) request was sent to NHS Trusts across the UK. Unfortunately, the data retrieved from the FOI requests were unable to be compared to the data collected as part of this survey. This was because the information from the FOI requests were not able to be quantified. The information collected from the FOI requests is reported in Appendix 16.

4.3.4 Medical diagnoses

Patient respondents were asked to state the type(s) of functional disorder they have been diagnosed with, with the main diagnosis type being FND (n = 203). Eighty-nine respondents selected multiple diagnoses, five patients were unable to access services to receive an FND diagnosis and two were currently accessing services. A breakdown of diagnosis type is presented in Table 19.

Table 19: Have you received a diagnosis of any of the following conditions?

Functional disorder	**n**
Functional neurological disorder (FND)	213
Functional seizures/Psychogenic non-epileptic seizures (FS/PNES	82
Functional movement disorder (FMD)	33
Functional neurological symptom disorder (FNSD)	22
Dissociative neurological disorder	14
Conversion disorder (CD)	11
Multiple diagnoses of the above disorders	89
Currently accessing services to receive a diagnosis	5
I have been unable to access services to receive an FND or similar diagnosis	5
Prefer not to say	2
Don't know	1

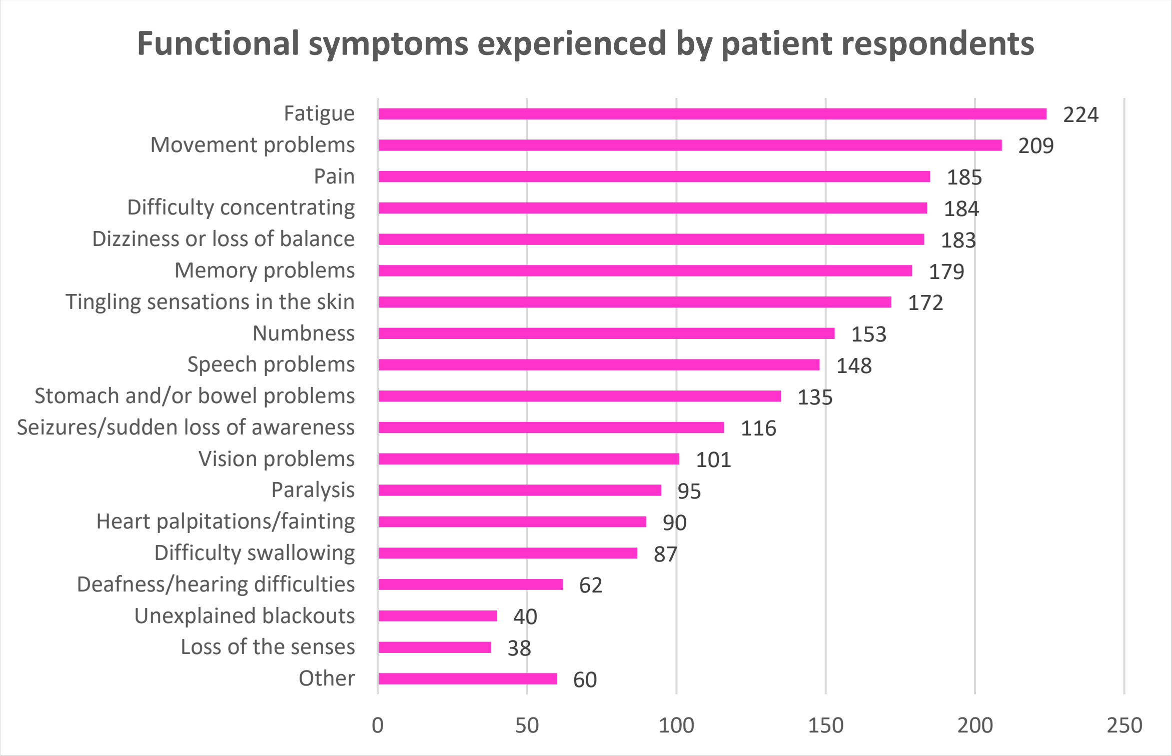
Participants were able to select more than one answer.

Patients who were unable to access services were asked for further information. Three respondents commented that they were placed on a waiting list to access services, one stated that there are limited services in Northern Ireland, and they must travel to England to be diagnosed, and one patient stated that their GP did not believe that the symptoms they were experiencing were caused by FND.

Patients were also asked if they have been diagnosed with any other medical conditions. 191 patients stated 'yes', with fibromyalgia (n = 25), asthma (n = 17), migraine (n = 15), depression (n = 12), anxiety (n = 12) and PTSD (n = 12) being the most reported conditions.

Patient respondents were asked to report which FND symptoms they experience. The most reported symptom was fatigue (n = 224; 87.2%), followed by movement problems (n = 209; 81.3%), pain (n = 185; 72%), difficulty concentrating (n = 184; 71.2%), dizziness and loss of balance (n = 183; 71.2%) and tingling sensations (n = 172; 66.9%). Sixty patients also reported experiencing 'other' symptoms, including bladder issues (n = 10; 3.9%), headaches (n = 5; 1.9%), tics (n = 3; 1.7%) and gait issues (n = 3; 1.7%). Figure 14 provides a breakdown of the symptoms experienced by patients.

Figure 14: Functional symptoms experienced by patient respondents



Participants could select more than one answer

Patient respondents were asked whether they thought there were any specific events or issues related to the onset of FND symptoms and/or their diagnosis. Participants were able to report more than one potential trigger to their FND onset. 250 participants provided their thoughts, with the main potential triggers being pain or chronic pain (n = 103; 41.2%), stress (n = 100; 40%), a mental health condition (n = 92; 36.8%), physical illness (n = 75; 30%) and adverse childhood events (n = 73; 29.2%). Thirty-eight patients thought that other causes were related to their FND symptoms, including medication side effects (n = 8; 3.2%), autism (n = 4; 1.6%), vaccination side effects (n = 2; 0.8%) and injury (n = 2; 0.8%).

Table 20: Do you think any of the following are related to your FND diagnosis?

	N
Pain/chronic pain	103
Stress	100
Mental health condition	92
Headaches/migraines	76
Physical illness	75
Adverse childhood event (ACE)	73
PTSD	69
CFS/ME	52
Surgical operation	34
Inflammation	33
Infection	31
Accident(s)	30
Bereavement	30
Head trauma/brain injury	22
Stroke	4
I do not think any of these issues or events are related to my FND diagnosis	10
Other	38
Don't know	29
Missing	4
Prefer not to answer	1

Participants could select more than one answer.

Caregivers were asked if the person they support has received a functional disorder diagnosis. Thirty-three respondents stated yes, and one stated that they were currently accessing services to receive a diagnosis. Those who stated 'yes' also reported the type(s) of functional disorder the person they support was diagnosed with, with the main diagnosis type being FND (n = 24; 70.6%). Twelve respondents selected multiple diagnoses. A breakdown of diagnosis type can be found in Table 21.

Table 21: Has the person you provide support for received a diagnosis of any of the following conditions?

Functional disorder	**N**
Functional neurological disorder (FND)	24
Functional seizures (FS)	17
Functional movement disorder (FMD)	8
Dissociative neurological disorder	5
Multiple diagnoses of the above disorders	12

Participants could select more than one answer.

Year of diagnosis was provided by 31 caregiver respondents. Nine patients received their diagnosis between 2013-2019, 6 in 2020, 14 in 2021 and 2 in 2022. 209 patient respondents provided the date of their diagnosis. Seven were diagnosed between 2000 and 2009, 85 were diagnosed between 2010 and 2019, 23 were diagnosed in 2020, 69 were diagnosed in 2021 and 18 in 2022. Patients were asked whether they agree with their FND diagnosis. 210 patients provided a response, with 188 (81.7%) stating 'yes', and 42 (18.3%) stating 'no'. Those who disagreed with their FND diagnosis were asked to explain why. Some patients believed that they had another medical condition, or that not enough tests were completed to determine the FND diagnosis:

> *"Looking at other conditions I believe I have MS."* [PT1194]
>
> *"Not enough tests done to rule auto immune diseases out."* [PT1101]

Other patient respondents stated they did not think that FND is a 'real' disorder, they received an FND diagnosis because their symptoms did not fully fit with other disorders, or that their FND diagnosis was determined before any diagnostic tests took place:

> *"Even if FND is real (and there is no evidence to support this notion), the diagnostic criteria clearly state that no other cause should be identified. This is not the case for me."* [PT1270]
>
> *"It seemed [like] a category for those that don't fall neatly into other diagnosis."* [PT1055]
>
> *"It seems on reflection and research that my diagnosis was made before I set foot into the supposed Neurologists room."* [PT1189]

4.3.5 Impact of caregiving

Caregivers were asked to describe their relationship with the person they provide care for. Most stated that they provided care for their parent or parent-in-law (n = 10; 29.4%) or for their child or child-in-law (n = 15; 44.1%). Eight respondents (23.5%) provided care for their spouse or partner. One respondent did not answer the question.

Caregiver respondents were asked how long they have been providing support to the person with FND, and how many hours per week they spend in their caregiver role. Fifteen caregivers (44.1%) reported that they have been providing support for over five years, and 11 (32.4%) reported they provide over 50 hours of care per week. A detailed breakdown is provided in Tables 22 and 23.

Table 22: For how long have you provided support to the person with FND?

	n(%)
0-6 months	3 (8.8%)
6-12 months	4 (11.8%)
1-2 years	7 (20.6%)
2-5 years	5 (14.7%)
5+ years	15 (44.1%)

Table 23: On average, how many hours per week do you spend in your caregiver role?

	n(%)
0-9 hours	7 (20.6%)
10-19 hours	3 (8.8%)
20-34 hours	7 (20.6%)
35-49 hours	5 (14.7%)
50+ hours	11 (32.4%)
Missing	1 (2.9%)

Respondents were asked to describe the type of caregiving support they provide. The main caregiving support tasks included emotional support (n = 33), assisting with household tasks and personal errands (n = 26), and providing transport to appointments or visits (n = 28). Other support included social companionship (n = 24), assisting with medical treatments (n = 23), financial support (n = 22), arranging or assisting with professional care (n = 23), assisting with personal care (n = 19), speaking tasks (n = 1) and helping the person they support to move their wheelchair in and out of their car (n = 1).

Respondents were questioned about whether they had received support while being a caregiver. Fourteen caregivers had received support from family or friends and four had received carers allowance or benefits. Table 24 provides a breakdown of the respondents' answers.

Table 24: Have you received any of the following support while being a caregiver?

	N
Support from family or friends	14
Carers allowance/benefits	4
Social work support	2
Attending a carers support group	1
Charity/organisation support	1
Personal counselling	1
Carer information/ training	0
Respite care	0
I have not received any support	11

Participants could select more than one answer.

Caregiver respondents were asked several questions which focused on the impact of their duties, the first of which enquired as to whether they felt they were doing all that they could to help the person they support. Twenty-seven respondents (79.4%) stated 'yes', four stated 'no' (11.8%) and the remaining three either preferred not to answer or did not answer the question (n = 3; 8.8%).

Secondly, respondents were questioned whether they felt overwhelmed as a caregiver, or if the person they support is a burden. Thirty-two caregivers answered this question, with 21 stating yes (61.8%). Eight stated no (23.5%) and three preferred not to answer or did not answer the question (14.7%). Respondents were also asked if they felt that they had enough time to look after themselves as well as the person they support. Only 15 carers stated yes, whereas 17 said no. Similarly, most caregivers (n = 26) stated that they need professional support to help the person they provide care for, whereas only six felt that they did not need professional support.

Twenty-five caregivers (73.5%) stated that being a caregiver had a negative impact on their daily life, whereas only five said that it did not (14.7%). Two respondents preferred not to answer this question (5.9%) and two did not answer (5.9%). Those who stated 'yes' were asked to explain how their caregiving duties had a negative impact. Some respondents described how caregiving had an emotional impact on themselves:

> *"Emotionally upsetting to see my child suffer paralysis, seizures and pain.*" [CG1215]

> *"… emotionally loss of friends and family support as no one understands how for example, you can book a holiday all paid for and then in their eyes just not go because they think that your daughter is just being selfish."* [CG1261]

Caregivers also reported how their duties had a financial impact:

> *"[The] Government only give me £110 a week to live on so am struggling to pay bills."* [CG1180]

> *"I am unable to work so I am not able to earn any money, my child is school age so I had those hours to work or do other things, now I don't as she doesn't go to school."* [CG1178]

Lastly, some caregivers commented on social isolation:

> *"Caring for my daughter has made me very isolated."* [CG1180]

> *"I'm happy to provide the support for my adult daughter but treatment options, knowledge and support have been very minimal leaving us very isolated with severe symptoms for the last 12 years."* [CG1028]

4.3.6 Healthcare worker knowledge and training

Healthcare workers were asked to provide their job title and clinical service type. Job titles are broken down below:

- Physiotherapist (n = 6; 21.4%)
- Clinical psychologist (n = 4; 14.3%)
- Consultant psychiatrists (n = 4; 14.3%)
- Nurse (including an alcohol specialist nurse and an advanced nurse practitioner, n = 3; 10.7%)
- Occupational therapist (OT; n = 2; 7.1%)
- General practitioner (GP; n = 2; 7.1%)
- Neurologist (n = 2; 7.1%)
- Speech and language therapist (SALT; n = 1; 3.6%)
- Consultant stroke physician (n = 1; 3.6%)
- Medical practitioner (n = 1; 3.6%)

- Support worker (n = 1; 3.6%)
- Consultant chemical pathologist (n = 1; 3.6%)

Seven respondents worked in a neurology service (including outpatients, rehab and neuropsychiatry; 25%), seven worked in a mental health or psychiatry service (including liaison and adult psychiatry; 25%), two worked in a persistent Physical Symptoms Service (7.1%), two worked in an acute hospital or stroke service (7.1%), one in general practice (3.6%), one in clinical health psychology (3.6%) and six (21.4%) reported they work in healthcare, the NHS (no further details provided), an outpatient service, a community trust or with non-epileptic attack disorder.

Healthcare workers were asked to report how many years they have been in clinical practice, and how long they have worked with FND patients. Twelve respondents had been in practice for 20 or more years (42.9%), however fourteen responded they have been working with FND patients for 0-5 years (50%). A detailed breakdown is presented below in Tables 25 and 26.

Table 25: How many years have you been in clinical practice?

Years worked in clinical practice	Chemical Pathologist	Clinical Psychologis	GP	Medical Practitioner	Neurologist	Nurse	OT	Physiotherapist	Psychiatrist	SALT	Stroke Physician	Support Worker	Total (%)
0-5 years								2					2 (7.1%)
6-10 years		2					1						3 (10.7%)
11-15 years		2				1		1	3				7 (25%)
16-20 years							1	2			1		4 (14.3%)
20+ years	1		2	1	2	2		1	1	1		1	12 (42.9%)

Table 26: How long have you been working with patients with FND?

Years worked with FND patients	Chemical Pathologist	Clinical Psychologis	GP	Medical Practitioner	Neurologist	Nurse	OT	Physiotherapist	Psychiatrist	SALT	Stroke Physician	Support Worker	Total (%)
0-5 years	1	2	1	1		1	1	4	1			1	14 (50%)
6-10 years		1				1	1		1		1		5 (17.9%)
11-15 years					1	1		1	1				4 (14.3%)
16-20 years										1			1 (3.6%)
20+ years		1	1		1				1				4 (14.3%)

Healthcare workers were asked to rate their FND knowledge and expertise. Most respondents stated they had moderate knowledge and expertise (n = 15; 53.6%; five physiotherapists, three psychiatrists, three nurses, two clinical psychologists, one OT and one SALT), whereas only six respondents stated they were very knowledgeable (21.4%; two neurologists, two clinical psychologists, one OT and one stroke physician). Two (7.1%; one medical practitioner and one GP) stated they had no knowledge of FND and five had some knowledge (one physiotherapist, psychiatrist, support worker, chemical pathologist and GP, respectively). Table 27 provides a breakdown of this rating.

Table 27: What is your knowledge/expertise of functional neurological disorder?

Knowledge/expertise of FND	n(%)
No knowledge/expertise	2 (7.1%)
Some knowledge/expertise	5 (17.9%)
Moderate knowledge/expertise	15 (53.6%)
Very knowledgeable and/or an expert	6 (21.4%)

Interestingly, only two of the healthcare worker respondents (a neurologist and a clinical psychologist) who had worked with FND patients for more than 20 years rated themselves as ‘very knowledgeable’. The remaining four respondents who rated themselves as ‘very knowledgeable’ had worked with FND patients for between 6 and 15 years; all worked in different clinical roles (clinical psychologist, occupational therapist, neurologist, and stroke physician). Most respondents who rated themselves with ‘no’ or ‘some’ knowledge/expertise of functional disorders had worked with FND patients for between 0 and 5 years, except one who had worked with these patients for more than 20 years.

Healthcare worker respondents were asked to report on who should be involved in the clinical management of FND. The most reported healthcare worker types are reported in Table 28.

Table 28: Which healthcare workers should be involved in the clinical management of FND?

Profession	n
Neurologist	23
Psychologist	22
Psychiatrist	22
Physiotherapist	20
Occupational therapist	19
Nurse	16
General practitioner	16
Counsellor	12
Speech and language therapist	3
Psychotherapist	1
A multi-disciplinary team should be involved	1
Stroke specialists	1

Finally, healthcare worker respondents were asked to describe the FND-specific training they have received and whether they felt it was sufficient. Twenty-five respondents provided a wide variety of answers. Four respondents stated they had received no formal training or none at all (16%), seven respondents had received training during their medical degree/speciality training (28%), and nine stated self-directed learning (36%). A detailed breakdown is provided in Table 29.

Table 29: Please describe the functional neurological disorder training you have received

Training type	Chemical Pathologist	Clinical Psychologist	GP	Medical Practitioner	Neurologist	Nurse	OT	Physiotherapist	Psychiatrist	SALT	Stroke Physician	Support Worker	n
Self-directed learning (e.g., reading research)	1	1	1		1		1	4					9
During general medical/speciality training				1		1		2	3				7
Attending online courses and/or webinars		1	1					5					7
Formal training received while in role								2		1	1	1	5
Attending conferences/symposiums						1	1		2		1		5
Member of FND society		2				1							3
Discussion with colleagues		1			1		1						3
CPD training		1							1				2
Training provided by a research trial								1					1
Mentorship and/or informal training in job role								1					1
FND therapists’ network		1											1
Attending a journal club								1					1
None/no formal training	1	1	1						1				4

Healthcare worker respondents were then asked if they received any training and supervision to deliver diagnostic assessments. Five respondents (occupational therapist n = 1, medical practitioner n = 1, nurse, GP n = 2) stated that to date, they had received very limited or no training or supervision to deliver diagnostic assessments for FND. In addition, four (psychiatrist n = 2, stroke physician n = 1, chemical pathologist n = 1) had only received training on the assessments in their general medical school/clinical training. Further details on training and supervision are provided below in Table 30.

Table 30: What training and/or supervision do you receive/have you received to deliver FND diagnostic assessment(s)?

Training received	**Chemical pathologist**	**GP**	**Medical practitioner**	**Neurologist**	**Nurse**	**OT**	**Physiotherapist**	**Psychiatrist**	**Stroke Physician**	**Total**
No formal training or supervision		2	1		1					4
General medical school or clinical training	1							2	1	4
Specialist training	1			1				2		4
Teaching/CPD events					1		1		1	3
Support or training from senior staff and colleagues							2			2
In-service training on recognising symptoms							2			2
Very limited training or supervision						1				1
Peer-to-peer learning							1			1

Participants could select more than one answer.

When asked if they deemed the FND-specific training they received as sufficient, only seven healthcare worker respondents (25%; physiotherapist n = 3, psychiatrist n = 1, support worker n = 1, stroke physician n = 1, neurologist n = 1) replied positively. Comparing these seven respondents to their answers given previously to ‘please describe the functional neurological disorder training you have received’, all had received detailed, clinical training (such as general medical school/speciality training, shadowing and training with experts, extensive research and training from a research trial). The remaining 21 respondents (75%) responded negatively. These 21 respondents were asked why they felt they had not received sufficient functional disorder training; 16 respondents provided an answer. These answers have been collated and are presented in Table 31.

Table 31: Please describe why you do not feel the FND-specific training you have received was sufficient

	Chemical pathologist	Clinical psychologist	Neurologist	Nurse	OT	Physiotherapist	Psychiatrist	SALT	n
No training was provided during my clinical training	1	2				2	2	1	8
There is always need for more training		1				1			2
There are no specific training courses				1					1
There are very limited courses available					1				1
There is a need for more opportunities to discuss and reflect on clinical practice				1					1
It was not really recognised when I trained			1						1
Evidence is limited		1							1
All clinical staff should receive training on FND		1							1

Participants could select more than one answer

4.3.7 Diagnostic methods

All participants were asked questions which focused on FND diagnostic processes. Patients were asked to report the duration from when they first reported their symptoms to diagnosis. 91 patients (35.4%) reported between 0 and 6 months. This figure is supported by the healthcare worker respondents directly involved in the diagnosis of FND (n = 10; neurologist n = 2, psychiatrist n = 4, nurse = 3, stroke physician n = 1) who reported the duration from referral to their service to patient diagnosis, with 60% (n = 6) also reporting 0-6 months. Services with the shortest referral time include community and acute stroke services, persistent physical symptoms services, neurology services and acute hospital services (0-6 months). General practice was reported as the longest referral time (19-24 months). A breakdown of the duration of time for diagnosis is reported in Table 32.

Table 32: Duration from first symptom reported/referral to service to diagnosis

	Patients (n = 257)	**Healthcare workers (n = 10)**
0-6 months	91 (35.4%)	6 (66.7%)
6-12 months	36 (14%)	1 (10%)
1-2 years	27 (10.5%)	0
2-5 years	39 (15.2%)	0
5+ years	42 (16.3%)	0
Don’t know	5 (1.9%)	0
Missing/Not applicable	17 (6.6%)	3 (30%)

Patient respondents were asked which healthcare workers were involved when undergoing diagnostic tests. The most common healthcare professions reported were neurologists (n = 233), GPs (n = 113) and emergency doctors (n = 79). Thirty-one respondents reported ‘other’, which included paramedics (n = 2), stroke consultants (n = 3), neurophysiologists (n = 2) and orthopaedic specialists (n = 2). The full list of healthcare workers is reported in Table 33.

Table 33: Which healthcare workers were involved when you were undergoing diagnostic tests?

	N
Neurologist	233
GP	113
A&E doctor	79
Psychologist	45
Psychiatrist	37
Nurse	36
Other	31
Missing	15
Paediatrician	2
Don’t know	1

Participants could select more than one answer.

The types of services attended during the diagnostic process were also reported. Neurology was the most reported service (n = 167) followed by Accident and Emergency (A&E) departments and GP offices (n = 116 and n = 116, respectively). Forty-six patients reported that they visited other services than those listed in Table 34. These services included occupational therapy (n = 8), general hospital wards (n = 7), radiology (n = 4), neuropsychiatric services (n = 2) and rheumatology (n = 2).

Table 34: Which services did you attend during the diagnostic process?

	N
Neurology	167
A&E department	116
GP office	116
Psychology or psychiatry	40
Epilepsy unit	27
Stroke unit	27
Phlebotomy	26
Paediatrics	3
Did not attend services	11
Don’t know	3
Other	46
Missing	13

Participants could select more than one answer.

In a similar vein, all healthcare worker respondents were asked several questions about the diagnostic processes in their service. Firstly, respondents were asked whether their service provides diagnostic tests or treatments for those with FND (or suspected FND), and then how many FND patients they personally see in their service per year. Seventeen respondents (60.7%) stated that their service provides diagnostic tests or treatments for (suspected) FND patients, whereas 11 (39.3%) replied that their service does not.

When asked how many FND patients they personally see in their service per year, only six respondents (21.4%) stated more than 50 patients in their service per year. Thirteen respondents reported 0 and 10 patients (46.4%). A breakdown of this information is provided in Table 35.

Table 35: How many FND patients do you personally see in your service per year?

Number of patients seen in service	n(%)
0-5	7 (25%)
6-10	6 (21.4%)
11-20	3 (10.7%)
21-30	3 (10.7%)
31-40	2 (7.1%)
41-50	1 (3.6%)
50+	6 (21.4%)

All participants were asked to detail the tools or assessments used to diagnose FND. The most reported diagnostic tests by patient respondents included neurological examination (n = 164), MRI scan (n = 141), blood sample (n = 135), positive clinical signs (n = 94), CT scans (n = 72) and EEG tests (n = 72). Caregivers were asked which tests were used to help diagnose the person they provide support for. The main diagnostic tests used were EEG (n = 18), MRI scans (n = 17), neurological exam (n = 17), blood samples (n = 17) and home-video recordings (n = 14).

All healthcare worker respondents were asked to report on which assessments they have used (or helped with) in the past two years to diagnose FND. Twenty-seven respondents answered this question, with the main diagnostic tools to diagnose or support the diagnosis of FND being a neurological exam (n = 12) and positive clinical signs (n = 11). Seven respondents used psychiatric assessments, five used CT scans and four used blood samples. For those directly involved in the diagnosis of FND (n = 10), the main tools included psychiatric assessments (n = 6), eye-witness exams (n = 5), positive signs (n = 5), CT scans (n = 4) and MRI scans (n = 4). Healthcare worker respondents were also asked which assessments they think are necessary to diagnose (or assist in diagnosing) FND. Neurological exams were deemed to be the most necessary assessment to diagnose FND (n = 14). MRI scans and positive clinical signs were reported by nine and ten respondents respectively, and eye-witness reports were reported by nine respondents. Three respondents selected ‘other’, reporting that any of the diagnostic tools may be necessary, as it depends on what the patient suspects is causing their symptoms, and multiple investigations may need to be conducted to rule-out other possible conditions. For those directly involved in the diagnosis of FND (n = 10), neurological exams (n = 6), MRI scans (n = 4), EEG (n = 4), eyewitness exams (n = 4) and psychiatric assessments (n = 4) were deemed the most deemed the most necessary tools for diagnosis.

Further information on diagnostic methods is reported in Table 36. Healthcare worker findings are provided in two ways; the first includes the full healthcare worker sample, the second includes only those directly involved in FND diagnosis.

Table 36: Diagnostic methods reported by survey participants

	Patient (n = 257)	Caregiver (n = 34)	Healthcare worker (n = 28)		Healthcare workers involved in FND diagnosis (n = 10)	
	What tests were used to help diagnose you with FND?	What tests were used to help diagnose the person you support?	Which assessments have you used, or helped with, in the past two years to diagnose a patient with FND?	Which assessments do you think are necessary to diagnose (or assist in diagnosing) a patient with FND?	Which assessments have you used, or helped with, in the past two years to diagnose a patient with FND?	Which assessments do you think are necessary to diagnose (or assist in diagnosing) a patient with FND?
Neurological exam	164 (63.8%)	17 (50%)	12 (42.9%)	14 (50%)	5 (50%)	6 (60%)
MRI scan	141 (54.9%)	17 (50%)	3 (10.7%)	9 (32.1%)	4 (40%)	4 (40%)
Blood sample	135 (52.5%)	17 (50%)	4 (14.3%)	5 (17.9%)	2 (20%)	3 (30%)
Positive clinical signs	94 (36.6%)	6 (17.6%)	11 (39.3%)	10 (35.7%)	5 (50%)	4 (40%)
CT scan	72 (28%)	7 (20.6%)	5 (17.9%)	7 (25%)	4 (40%)	3 (30%)
EEG	72 (28%)	18 (52.9%)	3 (10.7%)	6 (21.4%)	3 (30%)	4 (40%)
Home video recording	51 (19.8%)	14 (41.2%)	0	0	4 (40%)	0

	Patient (n = 257)	**Caregiver (n = 34)**	**Healthcare worker (n = 28)**		**Healthcare workers involved in FND diagnosis (n = 10)**	
	What tests were used to help diagnose you with FND?	**What tests were used to help diagnose the person you support?**	**Which assessments have you used, or helped with, in the past two years to diagnose a patient with FND?**	**Which assessments do you think are necessary to diagnose (or assist in diagnosing) a patient with FND?**	**Which assessments have you used, or helped with, in the past two years to diagnose a patient with FND?**	**Which assessments do you think are necessary to diagnose (or assist in diagnosing) a patient with FND?**
EMG/Nerve conduction test	40 (15.6%)	3 (8.8%)	1 (3.6%)	5 (17.6%)	1 (10%)	1 (10%)
Psychiatric assessment	33 (12.8%)	5 (14.7%)	7 (25%)	8 (28.6%)	6 (60%)	4 (40%))
ECG	31 (12.1%)	3 (8.8%)	1 (3.6%)	1 (3.6%)	1 (10%)	1 (10%)
fMRI	27 (10.5%)	2 (5.9%)	0	4 (14.3%)	0	1 (10%)
Neurophysiological assays	18 (7%)	1 (2.9%)	2 (7.1%)	4 (14.3%)	2 (20%)	1 (10%)
Other	18 (7%)	1 (2.9%)	2 (7.1%)	1 (3.6%)	0	0
Provocative testing	15 (5.8%)	0	2 (7.1%)	4 (14.3%)	1 (10%)	0
Lumbar puncture	11 (4.3%)	0	0	0	0	0

	Patient **(n = 257)**	**Caregiver** **(n = 34)**	**Healthcare worker** **(n = 28)**		**Healthcare workers involved in FND diagnosis (n = 10)**	
	What tests were used to help diagnose you with FND?	**What tests were used to help diagnose the person you support?**	**Which assessments have you used, or helped with, in the past two years to diagnose a patient with FND?**	**Which assessments do you think are necessary to diagnose (or assist in diagnosing) a patient with FND?**	**Which assessments have you used, or helped with, in the past two years to diagnose a patient with FND?**	**Which assessments do you think are necessary to diagnose (or assist in diagnosing) a patient with FND?**
VEM	10 (3.9%)	1 (2.9%)	1 (3.6%)	3 (10.7%)	1 (10%)	1 (10%)
vEEG	5 (1.9%)	1 (2.9%)	2 (7.1%)	2 (7.1%)	2 (20%)	2 (20%)
Don’t know	4 (1.6%)	1 (2.9%)	0	0	0	0
Serum levels	3 (1.2%)	0	1 (3.6%)	3 (10.7%)	1 (10%)	0
None	2 (0.8%)	0	0	0	0	0
PET scan	2 (0.8%)	0	1 (3.6%)	1 (3.6%)	1 (10%)	1 (10%)
Salivary cortisol test	1 (0.4%)	0	0	3 (10.7%)	0	0
Biomarkers	0	0	3 (10.7%)	2 (7.1%)	2 (20%)	1 (10%)
Eye-witness report	0	0	6 (21.4%)	9 (32.1%)	5 (50%)	3 (30%)
Prefer not to say	0	0	0	0	0	0

The most reported diagnostic methods are highlighted in pink.

Patients were asked which healthcare worker(s) gave them their FND diagnosis (Table 37). 220 patients received their diagnosis from a neurologist. Thirteen patients reported ‘other’, with two patients reporting that they were either informed via their discharge letter, or that their GP was informed in a letter by a specialist (who had not provided any diagnostic tests).

Table 37: Which healthcare worker(s) gave you your FND diagnosis?

Healthcare profession	n
Neurologist	220
Nurse	16
GP	12
Psychiatrist	9
Psychologist	8
A&E doctor	1
Paediatrician	1
Other	13
Don’t know	3
Not applicable	1
Prefer not to say	1
Missing	16

Participants could select more than one answer.

Participants were surveyed on the support provided and received during the diagnostic process. Healthcare workers were asked whether their service provides support to FND patients and their caregivers during the diagnostic process. Of those involved in the diagnostic process, four healthcare workers affirmed that their service provides support, two stated no, and four did not answer the question. One healthcare worker provided further information on what their service offers to support patients, explaining they schedule long appointments for discussion and signpost to online information.

Interestingly, the support currently being offered by services does not seem to be accessed by patients. Sixty-four patients attended support groups or accessed support pages (such as FND-specific groups on social media), 24 accessed charities or organisations, 16 received support from social services and 12 reported they had received support from family or friends. Patients who selected ‘other’ were asked what support they accessed; 10 patients stated they received help from health services or centres, and four had received talking therapy or counselling. Ten stated that they were not aware that support was available, or that there is no relevant support in their area. Fifty-two participants stated they did not access any support during their FND diagnostic journey. Patient respondents were asked to describe the support they would have liked to receive when they were undergoing diagnostic tests. 120 participants provided a response, with many focusing on medical or healthcare service support. Two common support types were having an experienced professional or specialist to conduct the diagnostic tests, and having the same healthcare worker reviewing the diagnostic tests:

> *"A professional experienced person to help me understand better."* [PT1146]

> *"I would have liked consistency with the same Dr and been reviewed at regular intervals."* [PT1241]

Other patients stated that follow-up appointments would be a suitable support type:

> *"Follow up with neuro, for new symptoms, see how you [sic] doing."* [PT1175]

> *"Properly assessed & appropriate care plan in place prior to discharge, adequate explanation of FND, management & support services, appropriate and timely follow-up."* [PT1238]

Patient respondents were also asked whether they felt that the healthcare worker(s) involved in the diagnostic test(s) were supportive of them and their condition. Of the 224 patients who answered the question, 93 stated 'yes' and 118 stated 'no'. Seven preferred to not answer the question. Patient respondents were asked to explain their answer. Those who selected 'yes' focused on how healthcare workers were reassuring, listened to them, and believed their symptoms and concerns:

> *"They made me feel like they believed me and were very supportive."* [PT1171]

> *"Yes there [sic] were all very reassuring. My neurologist talked me through FND in a way I could understand and gave me links to FND resources to digest in my own time."* [PT1151]

Contradicting these views, the patients who stated 'no' commented on how healthcare workers were dismissive or lacked compassion:

> *"A lot of nurses and some doctors were very dismissive and saying I was pretending or just another mental case."* [PT1187]

> *"Felt like the doctor had no time for me that I was a nuisance maybe even putting it on discharged home unable to speak properly or walk properly felt very disappointed."* [PT1104]

Patient respondents were asked whether they felt that the healthcare worker(s) who provided their FND diagnosis gave them enough information. Over 60% stated 'no' (n = 163; 63.4%) and 29.6% stated 'yes' (n = 76). Those who stated 'no' were asked to explain why. Over half of the participants (57%) who provided a reason reported that they *"just gave me a website link and told me to look it up"* [PT1092], whereas others received *"no information, just casually told you can get better, just don't think about it!"* [PT1101]

Patients were invited to report how they felt accessing healthcare services during their diagnostic journey. 151 patients provided an answer, with the majority (n = 106) leaving a negative remark. Many reported feelings of anxiety and embarrassment due to being dismissed by healthcare workers:

> *"I have never felt so dismissed and unheard in my life."* [PT1008]
>
> *"Horrible. Don't feel supported or understood. Have been told different information on cause by different doctors and outright dismissed."* [PT1277]

Others reported feeling that healthcare workers did not believe them, or thought that they were feigning their symptoms:

> *"I was treated very poorly and actually abused by some of the staff who believed that I was pretending to be paralysed for attention."* [PT1151]
>
> *"Not welcome, disregarded as a patient. Most doctors have never heard of the condition, so you have to explain what it is for them to just look at you like it's made up, offer no support."* [PT1122]
>
> "*Really unwell in hospital. Treated badly by neurologist as inpatient and outpatient. This reflected on the nursing care. Felt disbelieved."* [PT1285]

Several respondents reported mixed experiences when having to access multiple diagnostic services:

> *"GP amazing & supportive - neurology disgraceful."* [PT1253]
>
> *"Differing experiences. My initial GP visits were beyond awful, and have left me wary and sceptical. I received wonderful treatment at A&E and was kept in for 10 days for diagnostics."* [PT1195]

A small number of patients (n = 19) provided positive comments, who felt relieved or motivated from attending diagnostic services as it helped them to understand *“what was happening”* [PT1232]. Contrasting previously mentioned negative comments, some respondents also reported positive experiences with healthcare workers working in diagnostic services:

> *“Professor [redacted] treated and diagnosed me with great care and tact.”* [PT1084]
>
> *“I was very fortunate because my neurologist specialised in FND so I’ve always felt informed and listened to.”* [PT1045]

In line with the previous patient question, healthcare worker respondents were asked if they thought that the FND diagnostic processes their service uses are suitable. Of those directly involved in the diagnosis of FND, 7 respondents answered this question, with three stating ‘yes’, and four stating ‘no’. All of the ‘yes’ respondents described why they thought their service’s diagnostic process is suitable, stating that they have *“well trained clinicians”* [HCW1198] within their service and they *“use a multidisciplinary approach”* [HCW1223] when investigating and diagnosing FND. Those who stated ‘no’ described the lack of open and clear communication from healthcare workers, the lack of FND-specific training, and how *“there is very little treatment available for these patients”* [HCW1208].

Lastly, patient and caregiver respondents were asked on what, if anything, the health services they accessed could have done differently. While some participants provided positive comments, many felt that healthcare workers did not show them compassion or empathy, or were dismissive of their symptoms:

> *“Show more care and compassion. I wasn’t making it up but they treated me like I was putting it on.”* [PT1088]
>
> *“EMPATHY. Better understanding...I was told to get on with life and live how I am. It’s impossible being in pain, unable to function, when you can’t get the medical help needed.”* [PT1122]

Other patients explained that the healthcare workers who diagnosed them were not knowledgeable on the condition:

> *“It would of [sic] helped if he was more knowledgeable.”* [PT1107]
>
> *“A&E need to learn what FND is and what the symptoms are.”* [PT1058]

Caregivers focused on healthcare workers' negative attitudes, including how some implied that the person they support was malingering or that it was the patient's fault for their symptom onset:

> *"Not acted as if 'it was all in her head' and she was somehow responsible for creating the symptoms."* [CG1028]
>
> *"More professionalism from [doctors] as at one stage my husband was accused of being a malingerer…This had a major detrimental effect on my husband from which he still hasn't fully recovered."* [CG1168]

Two caregivers provided positive comments, with one stating their experience was positive only when a knowledgeable consultant was involved:

> *"There was a distinct lack of awareness of FND amongst the paediatric neurology community. We saw many different consultants before eventually finding one who could provide a diagnosis, and then she couldn't treat him. When we did find a consultant with the knowledge, experience and facilities to provide treatment, all went very smoothly and couldn't have been better."* [CG1126]

4.3.8 Treatments

All participants were surveyed on FND treatments. Patient respondents were asked to select the treatments (specifically for their FND diagnosis) they were currently receiving, or had received, since their FND diagnosis. The main treatments included medication (n = 80), physiotherapy (n = 78), cognitive behavioural therapy (CBT; n = 47), occupational therapy (n = 41) and educational websites (n = 31). 'Other treatments' included Botox, hydrotherapy, and graded exercise therapy. Reported complementary medicines included chiropractor appointments, meditation, acupuncture, vitamin supplements and CBD oil.

Patient respondents were also asked how long they had been undergoing these treatments for and whether they felt the treatments improved their FND symptoms. The average treatment duration was 13.7 weeks (range: 1-52) for physiotherapy, 117.2 weeks for medication (range: 4-572) and 16 weeks for CBT (range: 2-58). Caregiver participants were also asked to select the treatments the person they support has received. The main treatments included medication (n = 12), physiotherapy (n = 8), psychotherapy (n = 6) and CBT (n = 6). Six respondents stated the person they provide support for had received no treatments to date. Four reported the use of complementary therapies (cranial osteopathy, massage with counselling, acupuncture and chiropractic care).

Healthcare worker respondents were asked if their service provides treatment options for FND, and if applicable, which treatment options were offered by their service. For those who are directly involved in the treatment of FND (n = 19; physiotherapist n = 6, psychiatrist n = 4, clinical psychologist n = 4, OT n = 2, neurologist n = 2, SALT n = 1), a wide range of treatment options were reported, with occupational therapy (n = 11), physiotherapy (n = 11), psychoeducation (n = 10), CBT (n = 11) and medication (n = 10) being the main treatment options provided.

Healthcare workers were then asked to describe whether they thought the FND treatments offered by their service were effective. Of the 19 respondents directly involved in the treatment processes of FND, 13 (68.3%) answered, with 8 answering positively and 5 negatively. Those who answered 'no' were asked to describe why they did not think their service's treatments were effective. Answers focused on a lack of services or communication:

> *"Time restrictions, lack of communication between teams."* [HCW1279]

Healthcare worker respondents were also asked which treatment options should be used in the treatment of FND. For those directly involved in the treatment of FND, Occupational therapy (n = 13), psychoeducation (n = 14), physiotherapy (n = 13), psychotherapy (n = 13), educational websites (n = 12) and mindfulness-based therapy (n = 12) were the most selected treatment options. Two respondents reported that complementary medicine should be provided by services (acupuncture n = 2). A full breakdown of treatment options (alongside a selection of patient comments providing experiences of accessing treatments) is provided in Table 38, with current treatment options provided by services reported in comparison. Healthcare worker responses are reported as a whole group and those who are directly involved in the treatment of FND.

Table 38: Treatments reported by respondents

	Patient (n = 257)			**Caregiver (n = 34)**	**Healthcare worker (n = 28)**		**Healthcare workers involved in FND treatment (n = 19)**	
	Which treatment(s) have you received?	**Average duration (weeks/ range)**	**Do you feel that the treatment helped with your FND symptom(s)?**	**Has the person you support received any of the following treatments?**	**What treatments/ interventions does your service provide?**	**Which FND treatments/ interventions do you think should be utilised?**	**What treatments/ interventions does your service provide?**	**Which FND treatments/ interventions do you think should be utilised?**
Medication	80 (31.1%)	117.2 (4-572)	Yes (n = 17): *“Migraine medication helped control my paralysis’* [PT1153] No (n = 18): *“Pain meds don't work’* [PT1080] Prefer not to say (n = 5)	12 (35.3%)	14 (%)	13 (46.4%)	10 (52.6%)	10 (52.6%)

	Patient (n = 257)			**Caregiver (n = 34)**	**Healthcare worker (n = 28)**		**Healthcare workers involved in FND treatment (n = 19)**	
	Which treatment(s) have you received?	**Average duration (weeks/ range)**	**Do you feel that the treatment helped with your FND symptom(s)?**	**Has the person you support received any of the following treatments?**	**What treatments/ interventions does your service provide?**	**Which FND treatments/ interventions do you think should be utilised?**	**What treatments/ interventions does your service provide?**	**Which FND treatments/ interventions do you think should be utilised?**
			No comments provided (n = 40)					
Physiotherapy	78 (30.4%)	13.7 (1-52)	Yes (n = 27): *“Physio helped me walk a bit better”* [PT1046] *“Gave me confidence to keep trying to walk/move”* [PT1016] No (n = 23):	8 (23.5%)	15 (%)	17 (60.7%)	11 (57.9%)	13 (68.4%)

	Patient (n = 257)			**Caregiver (n = 34)**	**Healthcare worker (n = 28)**		**Healthcare workers involved in FND treatment (n = 19)**	
	Which treatment(s) have you received?	**Average duration (weeks/ range)**	**Do you feel that the treatment helped with your FND symptom(s)?**	**Has the person you support received any of the following treatments?**	**What treatments/ interventions does your service provide?**	**Which FND treatments/ interventions do you think should be utilised?**	**What treatments/ interventions does your service provide?**	**Which FND treatments/ interventions do you think should be utilised?**
			“…standard physio was totally inappropriate and indeed made matters worse” [PT1216] Prefer not to say (n = 5) No response (n = 23)					
CBT	47 (18.3%)	16 (2-58)	Yes (n = 15):	6 (17.6%)	13 (46.2%)	15 (53.6%)	11 (57.9%)	12 (63.2%)

	Patient (n = 257)			Caregiver (n = 34)	Healthcare worker (n = 28)		Healthcare workers involved in FND treatment (n = 19)	
	Which treatment(s) have you received?	**Average duration (weeks/ range)**	**Do you feel that the treatment helped with your FND symptom(s)?**	**Has the person you support received any of the following treatments?**	**What treatments/ interventions does your service provide?**	**Which FND treatments/ interventions do you think should be utilised?**	**What treatments/ interventions does your service provide?**	**Which FND treatments/ interventions do you think should be utilised?**
			"They helped me to work through the trauma of being diagnosed and what happened mentally afterwards" [PT1082] No (n = 11): *"The therapist had no clue about FND, and*					

	Patient (n = 257)			**Caregiver (n = 34)**	**Healthcare worker (n = 28)**		**Healthcare workers involved in FND treatment (n = 19)**	
	Which treatment(s) have you received?	**Average duration (weeks/ range)**	**Do you feel that the treatment helped with your FND symptom(s)?**	**Has the person you support received any of the following treatments?**	**What treatments/ interventions does your service provide?**	**Which FND treatments/ interventions do you think should be utilised?**	**What treatments/ interventions does your service provide?**	**Which FND treatments/ interventions do you think should be utilised?**
			just tried to show me how to manage a new disability” [PT1130] No comments provided (n = 21)					
Occupational therapy	41	7.6 (1-26)	Yes (n = 10): *“It helped me monitor my improvements & challenge my*	5	15	18	11	13

	Patient (n = 257)			**Caregiver (n = 34)**	**Healthcare worker (n = 28)**		**Healthcare workers involved in FND treatment (n = 19)**	
	Which treatment(s) have you received?	**Average duration (weeks/ range)**	**Do you feel that the treatment helped with your FND symptom(s)?**	**Has the person you support received any of the following treatments?**	**What treatments/ interventions does your service provide?**	**Which FND treatments/ interventions do you think should be utilised?**	**What treatments/ interventions does your service provide?**	**Which FND treatments/ interventions do you think should be utilised?**
			brain in ways I wouldn't have known to on my own" [PT1155] No (n = 5): *"OT (Community) is very old school…About as useful as a chocolate fireguard"* [PT1011]					

	Patient (n = 257)			Caregiver (n = 34)	Healthcare worker (n = 28)		Healthcare workers involved in FND treatment (n = 19)	
	Which treatment(s) have you received?	**Average duration (weeks/ range)**	**Do you feel that the treatment helped with your FND symptom(s)?**	**Has the person you support received any of the following treatments?**	**What treatments/ interventions does your service provide?**	**Which FND treatments/ interventions do you think should be utilised?**	**What treatments/ interventions does your service provide?**	**Which FND treatments/ interventions do you think should be utilised?**
			Prefer no to say (n = 2) No comments provided (n = 24)					
Educational website	31 (12.1%)	N/A	No (n = 2): *"It was a website"* [PT1194] No comments provided (n = 29)	4 (14.3%)	10 (35.7%)	16 (57.1%)	7 (36.8%)	12 (63.2%)

	Patient (n = 257)			Caregiver (n = 34)	Healthcare worker (n = 28)		Healthcare workers involved in FND treatment (n = 19)	
	Which treatment(s) have you received?	**Average duration (weeks/ range)**	**Do you feel that the treatment helped with your FND symptom(s)?**	**Has the person you support received any of the following treatments?**	**What treatments/ interventions does your service provide?**	**Which FND treatments/ interventions do you think should be utilised?**	**What treatments/ interventions does your service provide?**	**Which FND treatments/ interventions do you think should be utilised?**
Mindfulness -based therapy (MBT)	27 (10.5%)	42 (6-106)	Yes (n = 4): *“Allowed me to understand the benefit of acceptance of the condition and provided examples of mindfulness best suited to me”* [PT1041] No = 6:	2 (7.1%)	10 (35.7%)	16 (57.1%)	8 (42.1%)	10 (52.6%)

	Patient (n = 257)			Caregiver (n = 34)	Healthcare worker (n = 28)		Healthcare workers involved in FND treatment (n = 19)	
	Which treatment(s) have you received?	Average duration (weeks/ range)	Do you feel that the treatment helped with your FND symptom(s)?	Has the person you support received any of the following treatments?	What treatments/ interventions does your service provide?	Which FND treatments/ interventions do you think should be utilised?	What treatments/ interventions does your service provide?	Which FND treatments/ interventions do you think should be utilised?
			"It helped with anxiety but not the actual symptoms" [PT1272] Prefer not to say = 2 No comments provided (n = 15)					
Psychotherapy	23 (8.9%)	23 (6-50)	Yes (n = 8): *"It may be that it helped some*	6 (17.6%)	5 (17.9%)	17 (60.7%)	4 (21.1%)	13 (68.4%)

	Patient (n = 257)			**Caregiver (n = 34)**	**Healthcare worker (n = 28)**		**Healthcare workers involved in FND treatment (n = 19)**	
	Which treatment(s) have you received?	**Average duration (weeks/ range)**	**Do you feel that the treatment helped with your FND symptom(s)?**	**Has the person you support received any of the following treatments?**	**What treatments/ interventions does your service provide?**	**Which FND treatments/ interventions do you think should be utilised?**	**What treatments/ interventions does your service provide?**	**Which FND treatments/ interventions do you think should be utilised?**
			symptoms that have not been as bad. But my symptoms are erratic” [PT1029] No (n = 6): *“Discharged because I made no improvement in my sessions and was told someone else if*					

	Patient (n = 257)			**Caregiver (n = 34)**	**Healthcare worker (n = 28)**		**Healthcare workers involved in FND treatment (n = 19)**	
	Which treatment(s) have you received?	**Average duration (weeks/ range)**	**Do you feel that the treatment helped with your FND symptom(s)?**	**Has the person you support received any of the following treatments?**	**What treatments/ interventions does your service provide?**	**Which FND treatments/ interventions do you think should be utilised?**	**What treatments/ interventions does your service provide?**	**Which FND treatments/ interventions do you think should be utilised?**
			I gave it up to have my time and they'd improve. Felt like I was wasting their time" [PT1005] No comments provided (n = 9)					
Neuro-physiotherapy	15 (5.8%)	20.3 (1-104)	Yes (n = 10): *"Neuro physio helped me learn a few new*	0	0	0	0	0

	Patient (n = 257)			**Caregiver (n = 34)**	**Healthcare worker (n = 28)**		**Healthcare workers involved in FND treatment (n = 19)**	
	Which treatment(s) have you received?	**Average duration (weeks/ range)**	**Do you feel that the treatment helped with your FND symptom(s)?**	**Has the person you support received any of the following treatments?**	**What treatments/ interventions does your service provide?**	**Which FND treatments/ interventions do you think should be utilised?**	**What treatments/ interventions does your service provide?**	**Which FND treatments/ interventions do you think should be utilised?**
			movements and eased the decline of other movement...helped me understand that FND is real and believed me and explained why I couldn't do some things no longer" [PT1251]					

	Patient (n = 257)			**Caregiver (n = 34)**	**Healthcare worker (n = 28)**		**Healthcare workers involved in FND treatment (n = 19)**	
	Which treatment(s) have you received?	**Average duration (weeks/ range)**	**Do you feel that the treatment helped with your FND symptom(s)?**	**Has the person you support received any of the following treatments?**	**What treatments/ interventions does your service provide?**	**Which FND treatments/ interventions do you think should be utilised?**	**What treatments/ interventions does your service provide?**	**Which FND treatments/ interventions do you think should be utilised?**
			“They given me…ways to improve muscle strength” [PT1201] No (n= 4): *“Not enough sessions”* [PT1099] No comments provided (n = 1)					
Hypnotherapy/hypnosis	9 (3.5%)	7 (6-8)	Yes (n = 3):	1 (2.9%)	2 (7.1%)	7 (25%)	0	6

	Patient (n = 257)			**Caregiver (n = 34)**	**Healthcare worker (n = 28)**		**Healthcare workers involved in FND treatment (n = 19)**	
	Which treatment(s) have you received?	**Average duration (weeks/ range)**	**Do you feel that the treatment helped with your FND symptom(s)?**	**Has the person you support received any of the following treatments?**	**What treatments/ interventions does your service provide?**	**Which FND treatments/ interventions do you think should be utilised?**	**What treatments/ interventions does your service provide?**	**Which FND treatments/ interventions do you think should be utilised?**
			"The hypnotherapy helped" [PT1111] No (n = 2): *"…made my neurological symptoms far worse"* [PT1265] No comments provided (n = 4)					
Chronic pain	8 (3.1%)	N/A	No comments provided (n = 8)	1 (2.9%)	8 (28.6%)	13 (46.4%)	7 (36.8%)	10 (52.6%)

	Patient (n = 257)			**Caregiver (n = 34)**	**Healthcare worker (n = 28)**		**Healthcare workers involved in FND treatment (n = 19)**	
	Which treatment(s) have you received?	**Average duration (weeks/ range)**	**Do you feel that the treatment helped with your FND symptom(s)?**	**Has the person you support received any of the following treatments?**	**What treatments/ interventions does your service provide?**	**Which FND treatments/ interventions do you think should be utilised?**	**What treatments/ interventions does your service provide?**	**Which FND treatments/ interventions do you think should be utilised?**
rehabilitation programme								
Eye Movement Desensitisation and Reprocessing (EMDR)	7 (2.7%)	15 (2-28)	Yes (n = 2): *"Reduced intensity of jerks by managing anxiety"* [PT1037] No (n = 4): *"Absolutely no change in my*	3 (8.8%)	10 (35.7%)	10 (35.7%)	10 (52.6%)	10 (52.6%)

	Patient (n = 257)			Caregiver (n = 34)	Healthcare worker (n = 28)		Healthcare workers involved in FND treatment (n = 19)	
	Which treatment(s) have you received?	**Average duration (weeks/ range)**	**Do you feel that the treatment helped with your FND symptom(s)?**	**Has the person you support received any of the following treatments?**	**What treatments/ interventions does your service provide?**	**Which FND treatments/ interventions do you think should be utilised?**	**What treatments/ interventions does your service provide?**	**Which FND treatments/ interventions do you think should be utilised?**
			symptoms" [PT1142] No comments provided (n = 1)					
Neuropsychology	6 (2.3%)	6 (4-9)	Yes (n = 3): *"Helped me to stay in the moment. be more self loving"* [PT1198] No comments provided (n= 3)	0	0	0	0	0

	Patient (n = 257)			**Caregiver (n = 34)**	**Healthcare worker (n = 28)**		**Healthcare workers involved in FND treatment (n = 19)**	
	Which treatment(s) have you received?	**Average duration (weeks/ range)**	**Do you feel that the treatment helped with your FND symptom(s)?**	**Has the person you support received any of the following treatments?**	**What treatments/ interventions does your service provide?**	**Which FND treatments/ interventions do you think should be utilised?**	**What treatments/ interventions does your service provide?**	**Which FND treatments/ interventions do you think should be utilised?**
Psycho-dynamic therapy	6 (2.3%)	4 (N/A)	Yes (n = 2): No comments provided No (n = 1): *“All symptoms continued to arise and be prevalent”* [PT1113] No comments provided (n = 3)	1 (2.9%)	4 (11.8%)	11 (32.4%)	4 (21.1%)	8 (42.1%)

	Patient (n = 257)			Caregiver (n = 34)	Healthcare worker (n = 28)		Healthcare workers involved in FND treatment (n = 19)	
	Which treatment(s) have you received?	Average duration (weeks/ range)	Do you feel that the treatment helped with your FND symptom(s)?	Has the person you support received any of the following treatments?	What treatments/ interventions does your service provide?	Which FND treatments/ interventions do you think should be utilised?	What treatments/ interventions does your service provide?	Which FND treatments/ interventions do you think should be utilised?
Speech and Language Therapy	6 (2.3%)	6.3 (3-8)	Yes (n = 1): No comments provided No (n = 5): *"Helped that they were supportive but not the actual symptoms"* [PT1088]	0	0	1 (3.6%)	0	0
Dialectical behaviour	3 (1.2%)	8 (N/A)	No (n = 1): *"All symptoms continued to*	1 (2.9%)	4 (14.3%)	11 (39.3%)	3 (15.8%)	9 (47.4%)

	Patient (n = 257)			**Caregiver (n = 34)**	**Healthcare worker (n = 28)**		**Healthcare workers involved in FND treatment (n = 19)**	
	Which treatment(s) have you received?	**Average duration (weeks/ range)**	**Do you feel that the treatment helped with your FND symptom(s)?**	**Has the person you support received any of the following treatments?**	**What treatments/ interventions does your service provide?**	**Which FND treatments/ interventions do you think should be utilised?**	**What treatments/ interventions does your service provide?**	**Which FND treatments/ interventions do you think should be utilised?**
therapy (DBT)			*arise and be prevalent”* [PT1113] No comments provided (n = 2)					
Family therapy	3 (1.2%)	2 (N/A)	Yes (n = 1) No comment provided No (n = 2) *“Not helped the FND symptoms”* [PT1232]	0	0	0	0	10 (52.6%)

	Patient (n = 257)			**Caregiver (n = 34)**	**Healthcare worker (n = 28)**		**Healthcare workers involved in FND treatment (n = 19)**	
	Which treatment(s) have you received?	**Average duration (weeks/ range)**	**Do you feel that the treatment helped with your FND symptom(s)?**	**Has the person you support received any of the following treatments?**	**What treatments/ interventions does your service provide?**	**Which FND treatments/ interventions do you think should be utilised?**	**What treatments/ interventions does your service provide?**	**Which FND treatments/ interventions do you think should be utilised?**
Psycho-education	3 (1.2%)	8 (N/A)	Yes (n = 3): *"Helped me regulate my nervous system & feels good knowing why your body is doing x,y & z"* [PT1264]	1 (2.9%)	14 (50%)	18 (64.3%)	10 (52.6%)	14 (73.7%)
Psychiatry (no further information provided)	3 (1.2%)	No response provided	No comments provided (n = 3)	0	0	0	0	0

	Patient (n = 257)			**Caregiver (n = 34)**	**Healthcare worker (n = 28)**		**Healthcare workers involved in FND treatment (n = 19)**	
	Which treatment(s) have you received?	**Average duration (weeks/ range)**	**Do you feel that the treatment helped with your FND symptom(s)?**	**Has the person you support received any of the following treatments?**	**What treatments/ interventions does your service provide?**	**Which FND treatments/ interventions do you think should be utilised?**	**What treatments/ interventions does your service provide?**	**Which FND treatments/ interventions do you think should be utilised?**
Psychology (no further information provided)	3 (1.2%)	No response provided	Yes (n = 1): *"Psychology was beneficial, felt able to discuss issues from childhood to now"* [PT1281] No response (n = 2)	0	0	0	0	0
Acupuncture	2 (0.8%)	12 (N/A)	Yes (n = 1): *"Desensitised my nervous*	0	1 (3.6%)	9 (32.1%)	0	2 (10.5%)

	Patient (n = 257)			**Caregiver (n = 34)**	**Healthcare worker (n = 28)**		**Healthcare workers involved in FND treatment (n = 19)**	
	Which treatment(s) have you received?	**Average duration (weeks/ range)**	**Do you feel that the treatment helped with your FND symptom(s)?**	**Has the person you support received any of the following treatments?**	**What treatments/ interventions does your service provide?**	**Which FND treatments/ interventions do you think should be utilised?**	**What treatments/ interventions does your service provide?**	**Which FND treatments/ interventions do you think should be utilised?**
			system, supported me to make lifestyle changes and unlocked emotions” [PT1009] No (n = 1): *“I’d have 1 bad day after having it then 2 good days but then*					

	Patient (n = 257)			Caregiver (n = 34)	Healthcare worker (n = 28)		Healthcare workers involved in FND treatment (n = 19)	
	Which treatment(s) have you received?	Average duration (weeks/ range)	Do you feel that the treatment helped with your FND symptom(s)?	Has the person you support received any of the following treatments?	What treatments/ interventions does your service provide?	Which FND treatments/ interventions do you think should be utilised?	What treatments/ interventions does your service provide?	Which FND treatments/ interventions do you think should be utilised?
			revert back" [PT1048]					
Botox	2 (0.8%)	4 (1-7)	Yes (n = 2): *"It stops spasms"* [PT1055]	0	0	0	0	0
Chiropractor	2 (0.8%)	78 (N/A)	Yes (n = 2): *"Chiropractor has helped pain and stopped drop attacks"* [PT1190]	0	0	0	0	0

	Patient (n = 257)			**Caregiver (n = 34)**	**Healthcare worker (n = 28)**		**Healthcare workers involved in FND treatment (n = 19)**	
	Which treatment(s) have you received?	**Average duration (weeks/ range)**	**Do you feel that the treatment helped with your FND symptom(s)?**	**Has the person you support received any of the following treatments?**	**What treatments/ interventions does your service provide?**	**Which FND treatments/ interventions do you think should be utilised?**	**What treatments/ interventions does your service provide?**	**Which FND treatments/ interventions do you think should be utilised?**
Cranial Osteopathy	2 (0.8%)	312 (208-416)	Yes (n = 2): *"Cranial osteopathy calms down and reduces nervous system damage from the SSRI"* [PT1231]	0	0	0	0	0
Exposure therapy	2 (0.8%)	28 (N/A)	No (n = 2): *"Absolutely no change in my symptoms"* [PT1142]	0	0	0	0	0

	Patient (n = 257)			**Caregiver (n = 34)**	**Healthcare worker (n = 28)**		**Healthcare workers involved in FND treatment (n = 19)**	
	Which treatment(s) have you received?	**Average duration (weeks/ range)**	**Do you feel that the treatment helped with your FND symptom(s)?**	**Has the person you support received any of the following treatments?**	**What treatments/ interventions does your service provide?**	**Which FND treatments/ interventions do you think should be utilised?**	**What treatments/ interventions does your service provide?**	**Which FND treatments/ interventions do you think should be utilised?**
Repetitive Transcranial Magnetic Stimulation (rTMS)	2 (0.8%)	No response provided	No comments provided (n = 2)	0	0	3 (10.7%)	1 (5.3%)	2 (10.5%)
Scripted diagnosis	2 (0.8%)	No response provided	No comments provided (n = 2)	0	3 (10.7%)	8 (28.6%)	3 (15.8%)	7 (36.8%)
Vitamin supplements	2 (0.8%)	20.3 (6-34.5)	Yes (n = 2): *"This might blow your mind, but when you're B12 deficient*	0	0	0	0	0

	Patient (n = 257)			Caregiver (n = 34)	Healthcare worker (n = 28)		Healthcare workers involved in FND treatment (n = 19)	
	Which treatment(s) have you received?	**Average duration (weeks/ range)**	**Do you feel that the treatment helped with your FND symptom(s)?**	**Has the person you support received any of the following treatments?**	**What treatments/ interventions does your service provide?**	**Which FND treatments/ interventions do you think should be utilised?**	**What treatments/ interventions does your service provide?**	**Which FND treatments/ interventions do you think should be utilised?**
			and you get B12 jabs, your symptoms improve" [PT1270]					
Acceptance and Commitment Therapy	1 (0.4%)	40 (N/A)	Yes (n = 1): *"It was very helpful"* [PT1018]	0	0	0	0	0
CBD oil	1 (0.4%)	22 (N/A)	Yes (n = 1): *"CBD oil I feel helps to take the*	0	0	0	0	0

	Patient (n = 257)			Caregiver (n = 34)	Healthcare worker (n = 28)		Healthcare workers involved in FND treatment (n = 19)	
	Which treatment(s) have you received?	**Average duration (weeks/ range)**	**Do you feel that the treatment helped with your FND symptom(s)?**	**Has the person you support received any of the following treatments?**	**What treatments/ interventions does your service provide?**	**Which FND treatments/ interventions do you think should be utilised?**	**What treatments/ interventions does your service provide?**	**Which FND treatments/ interventions do you think should be utilised?**
			edge off” [PT1308]					
Counselling	1 (0.4%)	52 (N/A)	Yes (n = 1): No comment provided	0	0	0	0	0
Graded exercise therapy (GET)	1 (0.4%)	2 (N/A)	No (n = 1): *“Ineffective”* [PT1240]	0	0	0	0	0
Holocene method	1 (0.4%)	26 (N/A)	Yes (n = 1): *“I’m working with Dr [redacted]…I*	0	0	0	0	0

	Patient (n = 257)			**Caregiver (n = 34)**	**Healthcare worker (n = 28)**		**Healthcare workers involved in FND treatment (n = 19)**	
	Which treatment(s) have you received?	**Average duration (weeks/ range)**	**Do you feel that the treatment helped with your FND symptom(s)?**	**Has the person you support received any of the following treatments?**	**What treatments/ interventions does your service provide?**	**Which FND treatments/ interventions do you think should be utilised?**	**What treatments/ interventions does your service provide?**	**Which FND treatments/ interventions do you think should be utilised?**
			can't believe other professionals didn't use the techniques she does" [PT1050]					
Homeopathy	1 (0.4%)	26 (N/A)	Yes (n = 1): *"Homeopathy I think helped and got me back to being able to function enough*	0	0	0	0	0

	Patient (n = 257)			**Caregiver (n = 34)**	**Healthcare worker (n = 28)**		**Healthcare workers involved in FND treatment (n = 19)**	
	Which treatment(s) have you received?	**Average duration (weeks/ range)**	**Do you feel that the treatment helped with your FND symptom(s)?**	**Has the person you support received any of the following treatments?**	**What treatments/ interventions does your service provide?**	**Which FND treatments/ interventions do you think should be utilised?**	**What treatments/ interventions does your service provide?**	**Which FND treatments/ interventions do you think should be utilised?**
			to get a job” [PT1048]					
Internal family systems therapy	1 (0.4%)	52 (N/A)	Yes (n = 1): *“Understood my stress better”* [PT1062]	0	0	0	0	0
Light therapy	1 (0.4%)	No response provided	Yes (n = 1): *“Shining [a] light in my eye has made me not as sensitive to light but hasn't taken it totally away as*	0	0	0	0	0

	Patient (n = 257)			**Caregiver (n = 34)**	**Healthcare worker (n = 28)**		**Healthcare workers involved in FND treatment (n = 19)**	
	Which treatment(s) have you received?	**Average duration (weeks/ range)**	**Do you feel that the treatment helped with your FND symptom(s)?**	**Has the person you support received any of the following treatments?**	**What treatments/ interventions does your service provide?**	**Which FND treatments/ interventions do you think should be utilised?**	**What treatments/ interventions does your service provide?**	**Which FND treatments/ interventions do you think should be utilised?**
			stress also brings it on” [PT1112]					
Reflexology	1 (0.4%)	34.5 (N/A)	Yes (n = 1): *“Reflexology helped pain and improved sleep”* [PT1190]	0	0	0	0	0
Adjunctive physical activity (APA)	0	N/A	N/A	0	3 (10.7%)	8 (28.6%)	2 (10.5%)	6 (31.6%)

	Patient (n = 257)			Caregiver (n = 34)	Healthcare worker (n = 28)		Healthcare workers involved in FND treatment (n = 19)	
	Which treatment(s) have you received?	Average duration (weeks/ range)	Do you feel that the treatment helped with your FND symptom(s)?	Has the person you support received any of the following treatments?	What treatments/ interventions does your service provide?	Which FND treatments/ interventions do you think should be utilised?	What treatments/ interventions does your service provide?	Which FND treatments/ interventions do you think should be utilised?
Motivational interviewing	0	N/A	N/A	0	8 (28.6%)	11 (39.3%)	7 (36.8%)	11 (57.9%)
Non-invasive brain stimulation	0	N/A	N/A	2 (5.9%)	2 (7.1%)	3 (10.7%)	0	2 (10.5%)
Virtual Reality based Mirror Visual Feedback (VR-MVF)	0	N/A	N/A	0	2 (7.1%)	3 (10.7%)	0	2 (10.5%)

	Patient (n = 257)			Caregiver (n = 34)	Healthcare worker (n = 28)		Healthcare workers involved in FND treatment (n = 19)	
	Which treatment(s) have you received?	**Average duration (weeks/ range)**	**Do you feel that the treatment helped with your FND symptom(s)?**	**Has the person you support received any of the following treatments?**	**What treatments/ interventions does your service provide?**	**Which FND treatments/ interventions do you think should be utilised?**	**What treatments/ interventions does your service provide?**	**Which FND treatments/ interventions do you think should be utilised?**
No treatment to date	21	N/A	N/A	6	N/A	N/A	N/A	N/A

All respondents were surveyed on the shared decision-making process between healthcare workers and patients (and if applicable, caregivers). Answers to whether shared decision-making occurred were mixed. 154 patients answered, with 65 (42.2%) stating 'yes', 73 (47.4%) stating 'no', and 16 (10.3%) preferring not to say. Many of the patient respondents (who agreed that shared decision-making occurred) described how healthcare workers communicated with them and their caregivers, and kept them involved in the treatment process:

> *"Yes my team have been amazing I can't fault them. They even explained to my son who has Asperger's and is in his 20's they took the time to explain in a way that he could understand."* [PT1045]
>
> *"[My] wife was present with consultant discussing treatment and involved in discussion."* [PT1212]

In contrast, the patient respondents who did not agree that shared decision-making took place focused on a lack of involvement and communication from healthcare workers:

> *"Thry [sic] didn't ask me what I thought I needed. Everything was their decision and nothing I said was taken into consideration."* [PT1005]
>
> *"No communication with me at all, professionals decided themselves."* [PT1113]

Caregivers were also asked if they felt that the healthcare workers involved them (and the person they provide support for) in deciding the type of support or treatment to be put in place. Twenty-six respondents answered this question, with 10 stating yes, but 16 stating no. A small number of respondents provided an explanation for why they responded positively, with some stating that they did not initially feel that they were involved in the shared decision-making process:

> *"But only at the stage I pushed for specialist diagnosis in London- until then I was treated as part of the problem as if I was causing the 'anxiety' symptoms apparently causing my daughters symptoms."* [CG1028]

Only eight caregivers felt that healthcare workers were supportive of themselves and the person they supported when they were given the FND diagnosis, whereas eighteen respondents felt that healthcare workers were not supportive. Respondents were asked to describe why they felt this way, with many commenting on how they received little or no support:

> *"No support or treatment was offered for this life changing cruel illness."* [CG1167]

> *“Not enough support or information was given about diagnosis. After some initial short term help from psychologist and appointment with consultant at [hospital name redacted] we were left to get on with it.”* [CG1168]

Other respondents commented on how healthcare workers were dismissive or were not communicative:

> *“The neurologist just kept saying it was psychological and was dismissive.”* [CG1180]

> *“When the initial diagnosis was made my daughter did not feel that she was listened to.”* [CG1069]

All healthcare workers were questioned whether they felt that their service involves patients and caregivers (in the decision on what type of support or treatment the patient receives for their FND diagnosis) and why. All of the healthcare workers directly involved in the treatment for FND who responded to the question (n = 13) agreed their service involves patients and caregivers. However, when including all healthcare worker responses to this question, three responded negatively. Those who responded positively focused on *“collaborative decision-making in assessments”* [HCW1258] and *“collaborative formulation and discussion re treatment options and decisions re. what is most appropriate”* [HCW1035]. However, those who responded negatively focused on the lack of resources or support available for patients:

> *“Because services don’t exist.”* [HCW1013]

> *“There is very little support for patients with FND. Local IAPT service purports to offer treatment for long term conditions. However, I suspect that these patients are often not well supported in IAPT due to comorbid self-harming behaviours.”* [HCW1208]

Following on from this question, healthcare workers were asked if they felt that new approaches or treatments need to be implemented into services to support FND patients. Twenty-three respondents answered (including 14 directly involved in FND treatment processes), all stating ‘yes’. Eighteen respondents provided a response describing why, with some focusing on *“better outcomes”* [HCW1279] and others focusing on the implementation of multidisciplinary teams (MDTs):

> *“Needs [an] MDT approach and holistic care (physical and psychological therapies together).*” [HCW1205]

Lastly, all respondents were asked if they had any final experiences or perspectives they would like to share. In total, 193 respondents (caregivers n = 21, patients n = 157, healthcare workers n = 15) provided comments. A small minority of patients provided positive feedback (n = 12), which mainly focused on the support provided by healthcare workers or the effectiveness of treatments:

> *"My GP [and] rheumatologist are very supportive."* [PT1147]

> *"The [name redacted] hospital run an FND rehabilitation course with a multidisciplinary team. This course literally changed my life and made my quality of life so much better."* [PT1171]

However, many patient respondents provided negative experiences. Respondents stated how they felt alone, isolated or abandoned after they had received their FND diagnosis:

> *"I've never had one follow up call from the GP, I just feel abandoned with symptoms that if they had a label such as 'MS' or 'stroke', would be treated with deference and respect. Instead, they treat me like some sort of mad hypochondriac."* [PT1195]

> *"I just feel we are abandoned after diagnosis and I felt really scared."* [PT1146]

Other patients focused on the stigma and negative attitudes they experienced when accessing services:

> *"More understanding from medical staff as I have had paramedics tell me that I'm faking it it's in my head to and staff just putting me in a cubicle and leaving me for hours."* [PT1044]

> *"I still feel ashamed to talk about it as my GP says it's not a real illness."* [PT1081]

Lastly, patients commented on the *"lack of NHS support"* [PT1089] and resources available for FND:

> *"Treatment seems to depend on region. In [town redacted] Scotland help is poor/ non-existent."* [PT1267]

> *"The lack of ANY rehab facilities in Ireland and a complete ignorance of the disorder in the health service here are major obstacles."* [PT1059]

Similar to the patient respondents, many caregiver experiences focused on the lack of support, feelings of isolation, negative attitudes and further training and education needs for healthcare workers:

> *“The neurologist’s attitude was deplorable, my daughter had already been bedbound for 18 years with M.E./CFS and this diagnosis was delivered in such a “your [sic] wasting my time” off hand manner, so [no] help or support offered - told to look up a website!!!!.”* [CG1167]

> *“I feel more training on understanding the condition especially when there are other conditions to contend with, would be helpful. Not everyone is going to present the same.”* [CG1002]

> *“Our experience has been very traumatic for both my daughter and myself. It was and has been very isolating. The general lack of understanding that appears to still be an issue in the general medical field is of huge concern.”* [CG1028]

A small number of healthcare worker responses focused on emotions, with healthcare workers feeling “*frustrated for [patients]”* [HCW1278] and *“terribly sad”* [HCW1188]. One respondent stated how it *“can be emotionally draining [as FND] patients take up a lot of our time”* [HCW1307]. Healthcare workers felt worried that the diagnostic process is typically slow, FND outcomes are worse than ischaemic strokes and that they did not have access to services to refer patients. Other healthcare worker responses focused on the limited availability of treatment options or support for patients when they receive their FND diagnosis:

> *“No support from mental health services.”* [HCW1226]

> “*Patients just don’t have follow up.”* [HCW1202]

Finally, MDT approaches were described by healthcare workers. Some respondents remarked on the positive aspects of utilising an MDT approach, including:

> *“I think an MDT approach with joined up working between primary and secondary care will be most helpful. Too often people with FND fall between the gaps between physical and mental health care when in fact an integrative approach is needed.”* [HCW1280]

> *“…services to address the needs of patients with FND are virtually non-existent. This needs to be addressed with the commissioning of multidisciplinary holistic and evidence-based services. I often feel that I have nothing to offer these patients.”* [HCW1223].

4.4 Content analysis

As a large amount of data were provided in the survey responses, a content analysis was conducted using the qualitative data derived from the free text responses. The methods used to conduct the analysis are presented in Chapter 3. This analysis was both inductive and deductive.

The analysis was conducted in three stages:

1) Word categorisation
2) Meaning unit and theme development
3) Word frequency count

Word categorisations were established using a priori coding; the categories were chosen from the scoping review findings (Chapter 2) and the questions presented in this survey study. This is because the scoping review and questions were informed by recent evidence and research.

Once established, the qualitative data collected in the survey were read and re-read by two researchers (the author, along with a mental health practitioner with a qualitative research background). This allowed the researchers to be fully immersed in the data. Once immersed, the text was sorted into manageable ‘meaning units’ (for this content analysis, the meaning units were part or full sentences) and then coded in relation to the word categories identified previously. The list, which describes each code, is reported in Appendix 7.

To ensure that no data were missed, unsorted texts were re-read to check if they should be included in the analysis. One meaning unit was found to be relevant during this check. The meaning units were then grouped into themes and sub-themes relating to the original word categorisations.

In total, 1,618 pieces of qualitative data were retrieved from the survey, and 1,387 were included in the content analysis.

The word categorisations are presented below (in Table 39), alongside the themes derived from the data.

Table 39: Content analysis - word/concept categorisations and themes

Categories	Themes
The impact of communication and information sharing	Patient-healthcare worker relationship Professional behaviour when communicating with patients and caregivers Shared decision-making
Accessing treatments	Ability to provide treatments Ongoing support
The impact of FND	Impact on mental health Impact on emotions and feelings Impact on everyday life
FND knowledge and education	Lack of knowledge Education and training
Barriers to accessing resources	Inability to access services Resource waste Waiting times
Experiences of the FND diagnosis	Experiences of diagnostic testing Misdiagnosis

To examine which themes were the most reported in the survey answers, the frequency of the word categorisations in the themes were counted. A context search followed the frequency count to check the consistency of the usage of the included word categorisations (Mills et al., 2010). Table 40 below shows the frequency of each word categorisations in the themes, alongside the number of participants reporting the categorisation.

Table 40: Frequency of categorisations

Theme	Sub-theme	Code	Code frequency	Sub-theme frequency	Theme frequency total	Number of participants
Impact of communication and information sharing	Professional behaviour when communicating with patients and caregivers	Communication, attitudes, and behaviour	163	272	587	216
		Malingering and stigma	96			
		Impact of negative comments/behaviours from healthcare workers	13			
	Patient-healthcare worker relationship	Relationship development	81	266		
		Lack of information communicated	108			
		How information is communicated	77			

Theme	**Sub-theme**	**Code**	**Code frequency**	**Sub-theme frequency**	**Theme frequency total**	**Number of participants**
	Shared decision-making	Collaboration	18	49		
		Involvement of patients in decision-making	31			
Accessing treatments	Ongoing support	Outside support	20	200	224	151
		Treatment support	119			
		Improvement in treatment support	33			
		Healthcare worker support	28			
	Ability to provide treatments	Treatment availability	15	24		

Theme	Sub-theme	Code	Code frequency	Sub-theme frequency	Theme frequency total	Number of participants
		Improvement in treatments being offered	9			
The impact of FND	Impact on emotions and feelings	Confusion and embarrassment	19	64	227	155
		Frustration	12			
		Reassured	9			
		Isolation	24			
	Impact on everyday life	Loss of trust	4	52		
		Health and wellbeing	24			
		Relationship breakdown	5			

Theme	Sub-theme	Code	Code frequency	Sub-theme frequency	Theme frequency total	Number of participants
		Financial loss	19			
	Impact on mental health	Increased anxiety	27	111		
		Negative mental health	84			
FND knowledge and education	Lack of knowledge	Knowledgeable healthcare workers	14	111	133	106
		Lack of healthcare worker knowledge	56			
		Lack of patient knowledge	15			
		Ignorance	26			
	Education and training	Lack of FND specific education	22	22		

Theme	Sub-theme	Code	Code frequency	Sub-theme frequency	Theme frequency total	Number of participants
Barriers to accessing resources	Waiting times	Lengthy waiting times	47	75	119	92
		Removal from waiting lists	1			
		Private healthcare	14			
		Results waiting time	3			
		Appointment times	10			
	Inability to access services	Appointment cancellations	1	36		
		Declined access to services	9			
		Postcode lottery	26			

Theme	**Sub-theme**	**Code**	**Code frequency**	**Sub-theme frequency**	**Theme frequency total**	**Number of participants**
	Resource waste	Wasting patient time	3	8		
		Overuse of resources	5			
Experiences of the FND diagnosis	Experiences of diagnostic testing	Rule-out diagnostic testing	37	55	97	73
		Ease of accessing services	14			
		Effect of FND diagnosis on other conditions	4			
	Misdiagnosis	FND misdiagnosis	18	42		
		Misdiagnosis of another condition	24			

Although Table 40 is useful in showing the frequency of each word categorisation mentioned in the survey responses, it is imperative to detail the experiences of the respondents to fully understand each categorisation/theme.

Each categorisation/theme and their associated sub-themes are provided below. The categorisations/themes have been prioritised by frequency of respondents.

4.4.1 Theme 1: The impact of communication and information sharing

The majority of survey participants (n = 216) commented on communication, focusing heavily on communication from healthcare workers. Most patient and caregiver responses were negative in nature, with comments centring on the lack of shared decision-making and professional behaviour.

4.4.1.1 Professional behaviour when communicating with patients and caregivers

It has been documented that the behaviour and attitudes of healthcare workers can impact patient outcomes, with those experiencing negative attitudes when receiving care being more likely to face issues with patient safety and have a negative outcome (Brooks et al., 2014). Although many responses were negative, some patient and caregiver respondents found support in understanding and compassionate healthcare workers, *"…They were absolutely wonderful, so understanding, supportive and helpful"* [PT1151], whereas others experienced mixed attitudes and behaviours from healthcare workers when seeking support:

> *"The neurology team are and understanding but GP and A&E and on occation [sic] paramedics were really rude about the condition and was called fake or worse on many occations [sic]."* [PT1165]
>
> *"…I unfortunately had many experiences like this with various members of the hospital staff so overall it was a very unsupportive environment but I did have a couple of carers and student nurses who were extremely supportive and kind and who went above and beyond so it wasn't all bad."* [PT1151]

However, many patient respondents experienced negative attitudes from healthcare workers and received accusations of malingering. Indeed, some patients provided detailed information on how they were treated in health services:

> *"Traumatic. Most neurological & A&E doctors have been extremely rude. One doctor in A&E assessed me, violently moving my body which caused my body to seize and fell to the floor. Luck[ily] my partner was there to catch me as he just stood and watched. Was then sent back in waiting room, had to lay on the floor, nurse said I*

> *shouldn't do that yet I had no choice. The doctor then came out with a clipboard and my blood test results, pointing at them one by one saying 'normal result', 'there's nothing wrong with you, my advice to you is to go home, I have patients to see'. This has stuck with me and completely lost my trust in doctors, they do not want to help FND patients."* [PT1122]

> *"…I was mostly treated like a hypochondriac [in hospital], I had a nurse shout at me to get up and walk and stop wasting their resources, I had a [member of staff] who kept 'testing' me she'd say I bet if I tickled your feet you'd move so she would poke and prod me and tickle me and put me in what would be an uncomfortable position leave things like the call bell out of reach etc. to see if I would move she had a very clear dislike for me, on my 13th day of paralysis I had to take a lot of laxatives after no bowel movements for 2 weeks as my bowels were also paralysed and the nurse was very cruel towards me when the laxatives began to work…which I understand but it wasn't a pleasant experience for me either she kept telling me I was disgusting and how badly it smelled and that I didn't need to call her in every hour to clean it away I should leave it a few hours etc., I had another nurse tell me that bladders don't just paralyse themselves and forcibly remove my catheter without my permission which wasn't picked up on until the doctor did his next round by which point my bladder was on the verge of explosion incredibly full and swollen and I was screaming in agony it took a loud telling off by the doctor for her to finally put it back in."* [PT1151]

Experiences of stigma were common. Numerous patient and caregiver participants commented on being ignored or dismissed by healthcare workers when trying to communicate with them, or how the healthcare workers implied the patient was malingering:

> *"Appallingly bad, with a few exceptions. GPs rude, dismissive and judgmental-looking for time off work, malingering, refused fit note, not a real condition. Respiratory consultant said due to anxiety & hyperventilating…Also told [it's] made up, psychiatric disorder, playing [the] martyr card etc."* [PT1238]

> *"The person doing the EEG was horrible. He made her situation much worse than it needed to be. This was because of his behavior and attitude towards her...Paramedics said 'she won't do it' like she was faking the symptoms. We also had the same in A&E..."* [CG1052]

Negative behaviours and beliefs had a direct negative impact on patients. Patients began to believe they were a *“nuisance”* [PT1104] or that they were “*wasting NHS money”* [PT1187]:

> *“It was rushed, with no explanation. Immediately made to feel I was wasting health practitioners time.”* [PT1272]
>
> *“Felt like the doctor had no time for me that I was a nuisance maybe even putting it on discharged home unable to speak properly or walk properly felt very disappointed.”* [PT1104]
>
> *“…not shouting: there is nothing wrong with you, you are waisting [sic] NHS money on tests, it is just attsntion [sic] seeking.”* [PT1030]

Worryingly, these behaviours and attitudes led to serious negative outcomes:

> *“Being believed is also important, with FND a lot of doctors & nurses I saw said I was making it up, which left my family and I feeling very upset and hopeless, even to the point where I felt like giving up and tried to end my life.”* [PT1031]
>
> *“More professionalism from Drs [needed] as at one stage my husband was accussed [sic] of being a malingerer. The Dr was made to apologise [sic] by the consultant. This had a major detrimental affect [sic] on my husband from which he still hasn’t fully recovered.”* [CG1168]
>
> *“It was really hard as some doctors don’t believe you…physio after [being] paralysed told me there was nothing wrong with me it was all in my head. It’s mentally destroying a health professional not believing you.”* [PT1112]

4.4.1.2 Patient-healthcare worker relationship

The patient-healthcare worker relationship (also known as the doctor-patient relationship) refers to how the patient and healthcare worker both accept the assistance of the healthcare worker and the acceptance of working with the patient. This leads to the development of a consensual, professional relationship incorporating loyalty, trust, mutual knowledge and regard (Chipidza et al., 2015, Ridd et al., 2009). The importance of the patient-healthcare worker relationship has been documented widely (Chipidza et al., 2015; Chen & LaFrance, 2016), alongside the way effective (or not so effective) communication impacts on how (and if) the patient-healthcare worker relationship develops. Healthcare worker respondents concentrated on how they provide information to patients, but provided little information on how they develop the patient-healthcare worker relationship:

> *“Joint sessions with family to advise how to support and involve in rehab.”* [HCW1036]

> *“We complete a “what matters to you” interview with a focus on person centred goals - education given on resources and avaliable [sic] treatments for them to try.”* [HCW1278]

> *“Rehab/discharge options are discussed with the patients. Often not discussed with families directly [sic] due to limitations around visiting hours.”* [HCW1307]

Patient and caregiver respondents focused on the frequency and quality of communication from healthcare workers when receiving the FND diagnosis. A minority of patients felt that they had received detailed communication from healthcare workers:

> *“One of the doctors on the ward during my month inpatient stay was really good and would go over my results in detail with me and would take to time to sit down and listen to any questions and ensure I had enough time to communicate as FND has effected [sic] my voice making me completely aphonic which was really good.”* [PT1004]

> *“I saw a fantastic neurologist at [place redacted] medical centre – [name redacted], neurologist. He explained to me the diagnosis of FND and why he came to that diagnosis. He gave me the neuro symptoms website, wrote a thorough detailed letter to my GP regarding my appointment and further steps to take.”* [PT1147]

Effective and in-depth communication is key in the development of the patient-healthcare worker relationship (Chipidza et al., 2015) and has been part of the evolution of patient-healthcare worker relationship models. For example, there is the active-passive model (where the healthcare worker acts upon the patient), and the mutual participation model (where there is an equal partnership between the patient and the healthcare worker; (Kaba and Sooriakumaran, 2007). However, many patient and caregiver experiences did not involve effective and in-depth communication. Indeed, some patients were given their diagnosis and not given any further information:

> *“I was not given any information, found out my diagnosis in the letter from neurologist.”* [PT1187]

> *“Didn’t hardly talk or explain anything to me. I had to find out from nurses on the ward why I was having this”* [PT1082]

The lack of information being communicated to patients may hinder the development of the patient-healthcare worker relationship, as one of the foundations of the relationship is mutual knowledge (Chipidza et al., 2015). Some patient and caregiver responses highlighted how this relationship can be developed by using effective and informative communication:

> *"More fully explained what the diagnosis means and how to manage it."* [CG1321]
>
> *"I would have preferred a more open conversation about what the tests were for, was it a process of elimination. Absolutely nothing was explained to me and I was left in the dark for months on end, even while in hospital I was never told what the tests were looking for."* [PT1195]

4.4.1.3 Shared decision-making

Shared decision-making involves both the healthcare worker and patient making informed healthcare decisions (Elwyn et al., 2010). Shared decision-making is a fundamental part of good clinical healthcare (Carmona et al., 2021) and can only take place when healthcare workers communicate effectively. All survey respondents were asked to detail their experiences of shared decision-making. Healthcare workers (who are directly involved in FND treatment processes) responses described how shared decision-making and collaboration takes place in their service:

> *"Patients are often accompanied to initial appointment and joint discussion takes place."* [HCW1279]
>
> *"Goal setting, education, family meetings, collaborative approach based on CBT model."* [HCW1259]

Patients focused on explaining their experiences of being diagnosed and being included in deciding which treatment options should be provided. Some patients explained how they were fully involved and informed during the diagnostic and treatment processes:

> *"They talked with me about everything and then we agreed on a plan going forward."* [PT1137]
>
> *"They listened to my concerns about medication and found a drug that suited me."* [PT1142]

Unfortunately, these positive experiences were not shared by the majority of patient respondents. Most reported negative experiences, where they were simply told the treatments they were going to receive, and were not given an opportunity to discuss their potential options:

> *"Thry [sic] didn't ask me what I thought I needed. Everything was their decision and nothing I said was taken into consideration."* [PT1005]

> *"Nobody asked me what I thought might help."* [PT1040]

Clear and effective communication is an essential part of good healthcare (Health Education England, 2023). However, the experiences given throughout the survey study demonstrate that effective and informative communication does not typically occur. Many patients reported how they experienced negative attitudes and unprofessional behaviour from healthcare workers and were frequently dismissed when trying to communicate. In addition, patient-healthcare worker relationships have been unable to develop, as well as shared decision-making, due to the lack of effective communication and information being provided to patients and caregivers.

4.4.2 Theme 2: Accessing treatments

As discussed in the scoping review (Chapter 2), there are a range of treatments available to support patients diagnosed with FND, including (but not limited to) physiotherapy, psychological interventions, and occupational therapy. This study surveyed the current treatments used in UK health services. Respondents described their experiences of FND treatments, including how patients were referred to treatment services, ongoing support and the ability of services to provide treatments.

4.4.2.1 Ongoing support

Many treatment-related responses concentrated on the ongoing support they have (or have not) received. Patients experienced support from healthcare workers, family or from support groups, both when discussing or receiving treatment for their FND symptoms:

> *"My GP has always been as supportive as possible. When I've discussed medication options with her she's always listened to things I've heard about through the Facebook FND groups and looked into/taken on board what I've found and how I feel about medications."* [PT1038]

> *"My partner is so supportive in every single way. Always attaches appointments with me and doctors who understands the diagnosis."* [PT1158]

> *"The most and best support we have had is from Facebook groups for FND. They have been a life saver, a lifeline with more help and answers than the NHS."* [CG1052]

However, others reported feeling a lack of support when going through the treatment process, leaving them feeling ignored or isolated:

> *"GP yes, physio [sic] to some extent. Rest of the bad bunch no support whatsoever."* [PT1256]

> *"I feel we have been left to bsttle [sic] on our own eith [sic] something that has been life changing and not offered information or support."* [CG1125]

These feelings of being unsupported and ignored led to some patients and caregivers seeking treatments independently. This included accessing private healthcare, contacting services' directly asking for a referral and searching for alternative/complementary therapy. Patients detailed how healthcare workers had a lack of knowledge regarding treatments, whereas others researched treatments due to feeling uninformed during their diagnosis:

> *"I had to look into and research my own options of treatment. I had to find out I should be getting neuro physio, neuro psychology etc. My neuro didn't tell me."* [PT1096]

> *"Frustrating and find I'm mainly sorting treatment myself, accessed online support such as FND Hope UK and FND Action."* [PT1021]

> *"I was given absolutely no information by any neurologist, and have not been informed of any management techniques other than reducing stress or doing CBT. I have had to create my own treatment plan with the help of the psychologist I see privately."* [PT1308]

Many respondents provided suggestions on how ongoing support throughout treatment could be improved. Interestingly, a high amount of participants suggested support from outside of the NHS, perhaps due to wanting a feeling of camaraderie from others in a similar situation:

> *"Support from patient support groups, this would have given me more knowledge and reassurance."* [PT1201]

> *"Support from charities/organisations and social services."* [PT1318]

> *"Signposted to reputable support groups, itr [sic] to meet others with same diagnosis."* [PT1272]

4.4.2.2 Ability to provide treatment

Although there are a variety of treatment options available for FND management, several survey respondents commented on services" lack of ability to provide treatment support. Respondents reported how there are little treatment options available, with some suggesting that the limited treatment options were due to a *“postcode lottery”* [PT1061] or lengthy *“waiting lists”* [PT1038]:

> *“The neuro [sic] told me I needed neuro physio and neuro pschology [sic] but none available [where I live] and told me to read a book.”* [PT1102]

> *“Once diagnosed there wasn’t much they said they can do.”* [PT1232]

Healthcare workers (who are involved in the delivery of FND treatments and support) provided suggestions on how to improve treatment options for FND patients, including utilising an MDT approach or specialist services:

> *“Increasing capacity for MDT working, more services, longer intervention time, more linked up services with other specialties such as pain/ortho/neurology.”* [HCW1259]

> *“However there is very little treatment available for these patients. There is a real potential for outpatient clinics.”* [HCW1208]

This smaller theme demonstrates a potential disconnect in service planning. Patient respondents were given little or no information on the treatment processes, and some chose to research available treatments and present them to a healthcare worker. Interestingly, patients were more likely to prefer support from organisations and charities, whereas healthcare workers suggested that an MDT approach would be more suitable for effective FND treatments.

4.4.3 Theme 3: Impact of FND

Patient and caregiver respondents were asked to describe the impact of both accessing healthcare services, and FND as a health condition. Not surprisingly, the majority of the responses were negative in nature, with patients feeling hopeless, isolated and emotional.

4.4.3.1 Impact on emotions and feelings

Patient respondents explained how they felt a vast array of emotions when accessing healthcare services, ranging from nervousness and feeling low, to reassured and relieved. Some respondents experienced feelings of confusion and embarrassment throughout the FND diagnostic and treatment processes due to dismissive behaviour from healthcare workers:

> *“The neurologist I saw the second time was but the first one was very dismissive and unsupportive saying it was in my mind and nothing wrong which was upsetting as I felt that I was making it up. I was confused and upset.”* [PT1150]

> *“Embarrassed. Most medical professionals said there’s nothing wrong with me. It’s all in the mind.”* [PT1081]

> *“Like I was not believed as tests were clear, felt dismissed and embarrassed.”* [PT1124]

Other patients explained how they felt frustrated or nervous due to being aware of the stigma associate with FND, or because of their interactions with healthcare workers:

> *”Frustrating as they made me feel that was exaggerating.”* [PT1044]

> *“Nervous as I knew the stigma that goes with FND.”* [PT1024]

> *“Before I received my diagnosis I was very nervous because it took two weeks of being an inpatient to receive my diagnosis and no one seemed to know what was wrong.”* [PT1201]

One participant felt so frustrated due to their experiences, that they illustrated their feelings and sent it directly to the author. The participant has given permission to include the images (provided below):

> *“…I became so frustrated with how badly treated FND patients are treated I put it into sketch form, I have emailed them to you. I hope this is ok.”* [PT1237]

Illustration 1: Depiction of living with FND

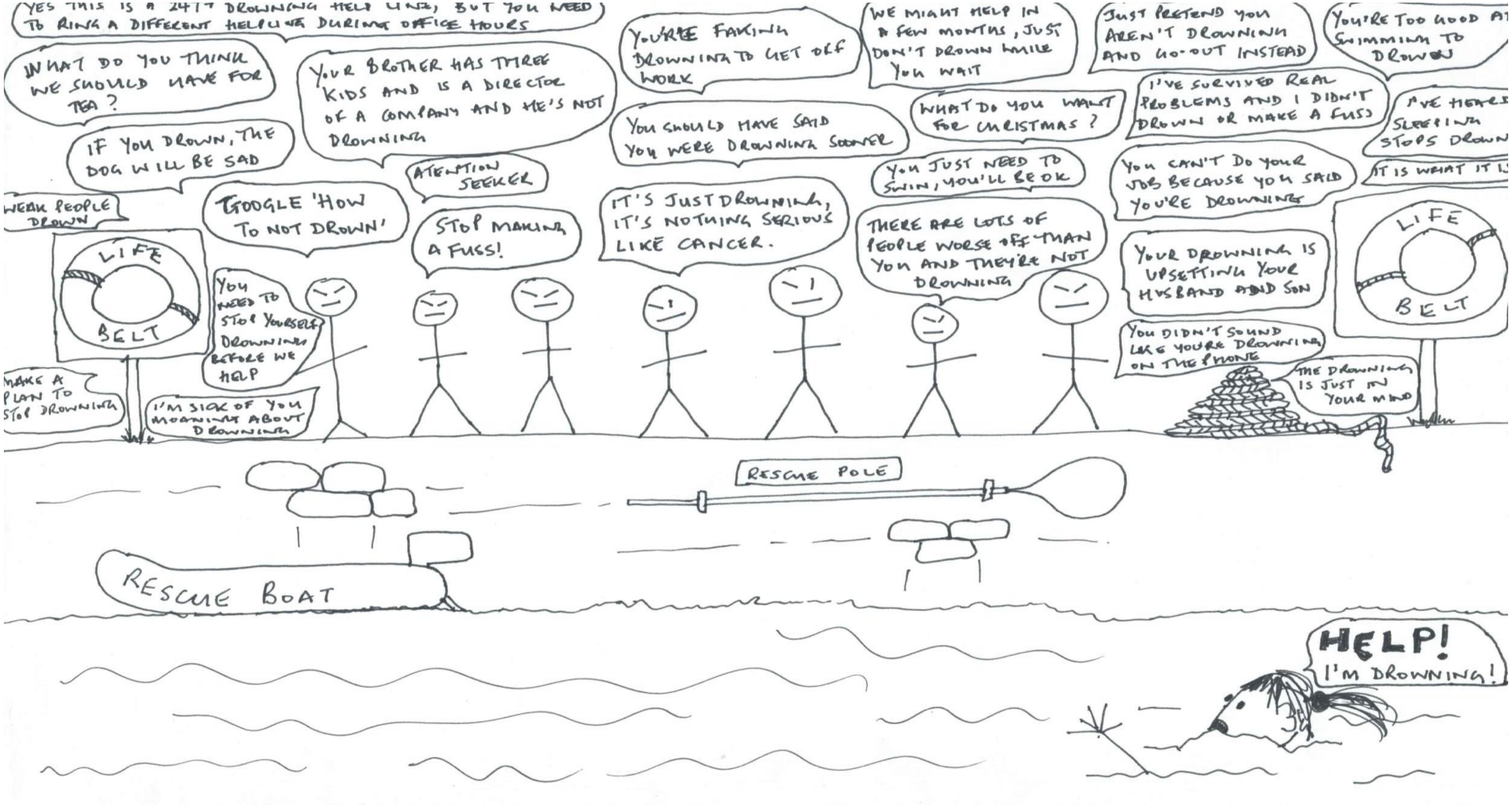
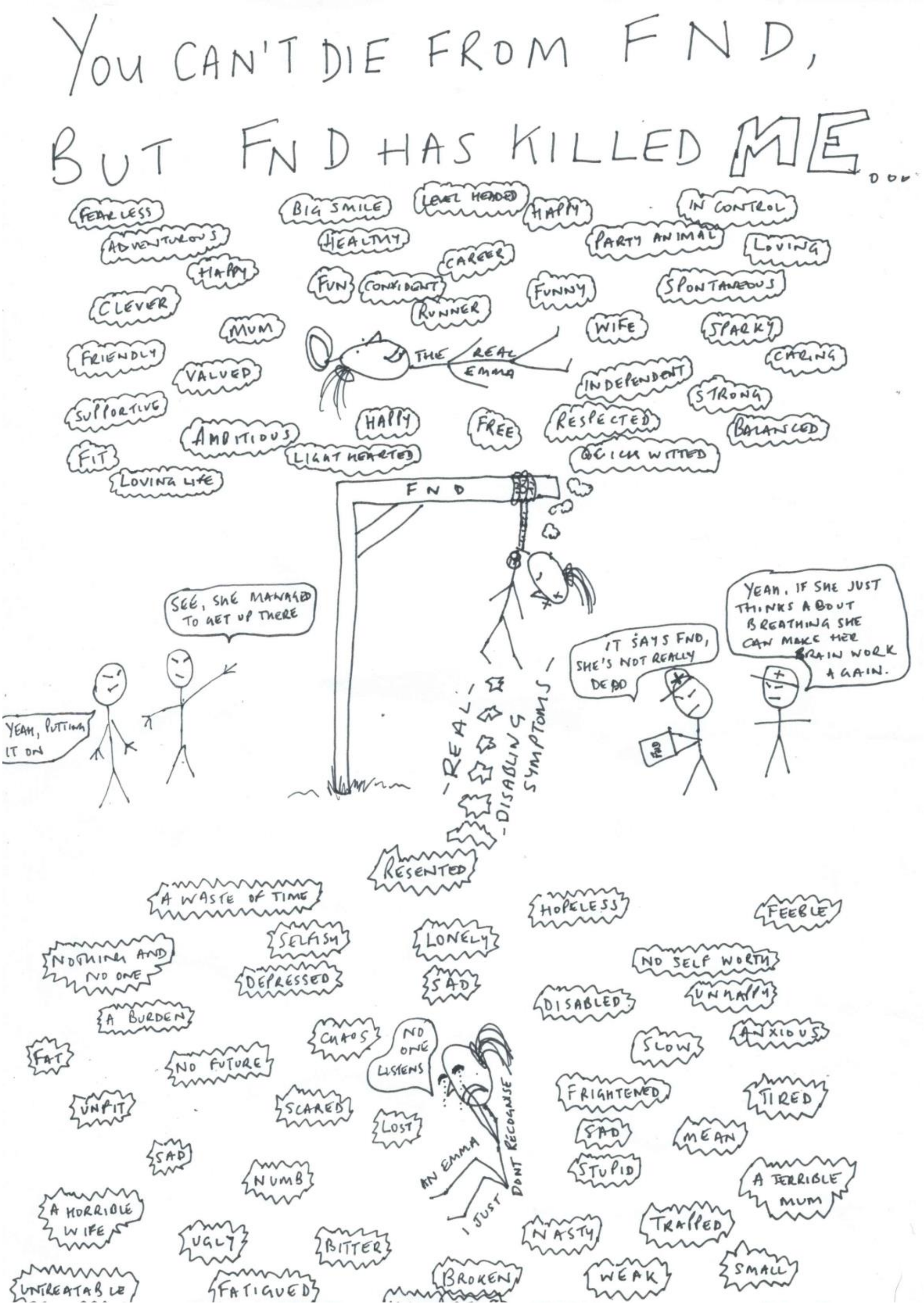


Illustration 2: Depiction of living with FND



Interestingly, a small number of patient respondents explained how they felt *“overwhelmed but reassured”* [PT1186], *“relieved”* [PT1232] or *“grateful”* [PT1041] when they received their diagnosis, perhaps due to now having a reason or name for the symptoms they had been experiencing.

Isolation was another fundamental feeling reported by participants. Caregivers and patients focused on how they felt abandoned by both healthcare workers and services. While a lack of support in services led to feelings of isolation, many participants reported on feeling isolated because of the condition itself:

> *“…I just feel abandoned with symptoms that if they had a label such as “MS” or “stroke”, would be treated with deference and respect.”* [PT1195]
>
> *“You feel very abandoned afterwards there is no way to get back in touch if have changes have to get [the] GP to re-refer.”* [PT1048]
>
> *“Our experience has been very traumatic for both my daughter and myself. It was and has been very isolating.”* [CG1028]

Finally, feelings of helplessness (caused by the impact of FND had on themselves or the person they provide support) were reported:

> *“I feel completely helpless. My partner is a shadow of herself and has tried to kill herself due to her declining symptoms. I frel [sic] like I‘ve been left alone to manage this and my health has suffered greatly. I feel completely alone, isolated and unsupported.”* [CG1211]
>
> *“Intimidated, not believed. Unheard. Frustrated. Helpless. Wanted to give up. No hope.”* [PT1031]

4.4.3.2 Impact on everyday life

The impact of accessing clinical services and having FND as a condition were elucidated by both patients and caregivers. Overwhelmingly, the impact on everyday life was extremely negative, with trust in healthcare services, finances, family life and health and wellbeing being corroded due to suffering from FND.

Some patients explained the link between their experiences of healthcare services and their loss of trust in services, leading them to refuse to attend future healthcare appointments. This refusal may in turn be detrimental to their health and wellbeing, and possibly future care planning/management:

> *“I genuinely find the whole experience difficult to talk about without getting upset, it’s been like a bomb going off in my life. At times I thought I’d never get back to health…I’m terrified how I come across to the doctor now, even when reporting a chest infection. My left hand now won’t open, and is becoming progressively worse. I’ve taken the decision just to try to get on with it without assistance, because going to the doctors is hugely upsetting now.”* [PT1195]

> *“Yes I feel like I’m now considered a malingerer with an hysterical womb, who has faked an illness because Johnny stole my lollipop when I was six in the playground. Yes I’m being flippant…I will unlikely contact my GP again other than to update my medical notes with additional symptom should/if they occur.”* [PT1189]

Other patients described the impact of FND on their health and wellbeing. Patients struggled with their symptoms and the unpredictability of when symptoms would occur. While some were able to accept the unpredictability, others found their newfound situation a great difficulty:

> *“No I think once you get your head around what it is. And realise you control it, it doesn’t control you. Learn your triggers. Every day I wake with something different wrong with me. It’s a challenge. Especially paralysis.”* [PT1023]

> *“Every day is an unknown and I really struggle with that. I am 21 and I feel like the past 5/6 years of my life have been clouded by these disorders. I can’t live my life to the fullest and my body constantly fails me.”* [PT1129]

> *“I am a million miles away from the person I used to be I can’t accept it I have to wear incontinence nappies as I don’t have the control over my bowels and bladder. I get confused I can’t remember simple things when n my family talk to me there is a delay in what they say before I understand it, it’s almost like reverting back to being a child, people treat you differently they think you don’t understand, sometimes I want to scream just to let them know I’m still here they just need to be a bit more patient.”* [PT1177]

As well as impairing their everyday life, FND impacted patients and caregivers” family and social life. Some respondents detailed the breakdown of friendships and relationships:

> *“Contributed to the breakdown of my Mariage [sic].”* [CG1145]

> *“It has ruined our lives, we get no support and I’m now housebound and feeling rejected because fnd has impacted greatly on our lives and jothing [sic] seems to be a positive anymore.”* [PT1005]

> *"I have always worked hard, had a good career, friends, relationship, social life…I was dismissed from my job on capability grounds as I was unable to return to work in 2013… I have lost my career, friends, relationship and had to move house as I could no longer manage the stairs."* [PT1221]

Lastly, respondents explained the negative financial impact of FND (both on themselves and their family):

> *"Caring for my daughter has made me ill due to the stress of looking after her with no breaks Government only give me £110 a week to live on so am struggling to pay bills."* [CG1180]

> *"People don't understand. I have had my ill health retirement declined. I am getting £149 a fortnight ESA & applied for PIP in April. My mum has been paying my mortgage & bills. I am going to have to sell my house."* [PT1054]

4.4.3.3 Impact on mental health

Patient and caregiver respondents described in detail how both accessing services, and FND as a health condition, affected their mental health and wellbeing. Many of the respondents focused on how their experiences with healthcare services impacted them, leading to them feeling *"anxious, stressed and scared*" [PT1096]. General mental health was widely reported throughout the survey responses. Indeed, patients reported how interactions with healthcare workers and services led to an increase in stress:

> *"It's mentally destroying a health professional not believing you"* [PT1112]

> *"Mostly horrific and incredibly stressful"* [PT1151]

From the experiences detailed above, services and healthcare workers, along with FND as a health condition, can have a large and detrimental impact on patients, caregivers and their families. Many respondents described how their everyday life has been adversely affected by FND, from feeling confused about their condition, to no longer being able to work or having relationships break down.

4.4.4 Theme 4: Knowledge and training

While only healthcare worker respondents were explicitly asked throughout the survey whether they felt they had enough training and knowledge to work confidently with FND patients, many patients and caregivers also provided their perspectives. Respondent perspectives and experiences typically focused on how there was a lack of knowledge or awareness of FND in healthcare services, or that there is insufficient education and training on the condition.

4.4.4.1 Lack of knowledge

All three respondent groups reported experiences and perspectives on the knowledge of healthcare workers and patients regarding FND. A small group of respondents commented on healthcare workers being knowledgeable about FND:

> *"When we did find a consultant with the knowledge, experience and facilities to provide treatment, all went very smoothly and couldn't have been better."* [CG1126]

> *"…my second neurologist is so much better and my specialist neuropsychiatrist is really knowledgeable too."* [PT1004]

However, a larger group of respondents reported a lack of FND knowledge from healthcare workers when accessing health services, with some stating only few are educated on the condition, whereas others were unaware or ignorant of the condition:

> *"Some wqrds [sic] were better than others and some staff were better and more understanding than others but that's just down to the lack of education around FND."* [PT1004]

> *"I am very engaged with increasing awareness about FND. I find the blanket of general ignorance about the disorder, among medical professionals quite alarming and very frequently I find myself explaining the disorder to them."* [PT1011]

> *"In my experience, general medical doctors and nurses have very little understanding of the condition. It is often misunderstood as all in the mind which isn't helpful for sufferers."* [PT1087]

Interestingly, patients also focused on their own lack of FND knowledge. Some stated they were given limited information from healthcare workers, leading them to independently research the condition to have a better understanding. This is concerning as they may access inaccurate (or evening potentially damaging) information:

> *"I was given a website address & discharged. I had to research FND alone to get any understanding."* [PT1081]

> *"It's hard to explain to people when you don't know yourself."* [PT1144]

4.4.4.2 Education and training

Analogous to the lack of knowledge sub-theme, respondents commented on FND specific education and training. One respondent provided information on the lack of sufficiently trained healthcare workers, whereas another detailed a new FND training approach:

> *“Unfortunately there are not enough trained medical professionals who know enough if anything at all about FND.”* [PT1111]

> *“I think now the FND clinic is providing training, L1,2,3 units will increase knowledge on approaches and treatments [sic] that can be used.”* [HCW1278]

Other participants discussed the need for specific FND education and training for healthcare workers to improve care and support:

> *“I feel more training on understanding the condition, especially when there are other conditions to contend with, would be helpful. Not everyone is going to present the same.”* [CG1002]

> *“I think there should be more educating in the medical profession about FND. I have spoken to MANY nurses who have never heard of it let alone the general public and employers, considering the rate of diagnosis that I have been told about.”* [PT1254]

> *“…need education to recognise and support.”* [HCW1198]

These comments were supported by healthcare worker respondents who provided experiences of their own FND-specific training. Some stated that FND *“was not really recognised when they trained”* [HCW1188] clinically, while others had to research the condition in order to educate themselves:

> *“[The] topic is not covered unless individuals have a desire to read up, research / attend training. Not covered at university or within house training at a local NHS level.”* [HCW1278]

Unsurprisingly, the lack of FND-specific education provided during clinical training led to many healthcare workers not having much knowledge on the condition. This has a knock-on effect on patients, as they experience a lack of understanding from healthcare workers and a delay in accessing services.

4.4.5 Theme 5: Resources

Treatment processes and resources were a focal point in many survey responses. Resources in this context refer to healthcare resources, including the availability of services, appointment availability, waiting times and resource waste. Although resources and effective resource use are a ‘hot topic’ in terms of healthcare and the NHS, it is worth noting for FND as a health condition due to the links between symptom onset and time to diagnosis on clinical outcomes (O'Keeffe et al., 2021).

4.4.5.1 Waiting times

Unsurprisingly, waiting times to access FND services were discussed widely. Respondents commented on their experiences of having to wait months, or even years, to access healthcare services:

> *"I am currently waiting to be seen in the FND clinic in Edinburgh as my Neurologist feels my case is too complex for him to deal with. I waited 21 months to see him, I don't know the waiting list for the Edinburgh clinic."* [PT1006]

> *"Takes too long to access Neurology. Took four years to get neuropsychologist appointment, and then because of lock down restrictions had two hour and a half sessions online. Still waiting for a follow up Neurology appointment I should have had in September 2021."* [PT1058]

Healthcare workers, caregivers and patient respondents provided experiences on the impact of waiting a long time for test results:

> *"If inpatinets [sic] it can block beds waiting [sic] for diagnostic tests, and can take time."* [HCW1307]

> *"The testing and waiting for the results and follow up appointments which occurred months later was difficult to wait without confirmation of the results."* [CG1069]

Some patient respondents commented about being removed from a waiting list without being consulted, therefore impacting their ability to access diagnostic and treatment services:

> *"A&E referred me to Neuro clinic for urgent appointment - put on waiting list and removed 12 months later. MHU unable to offer any assistance, at the time."* [PT1011]

> *"As an "urgent" case for neuro clinic (within 2 weeks) was put on 12 month waiting list for first appointment and removed from the list after 11 monthd [sic]."* [PT1059]

To bypass lengthy waiting times, a small number of participants paid to access private healthcare services, with some even getting into considerable debt:

> *"Went private as the wait was too long so borrowed money."* [PT1146]

> *"I see a psychologist privately, as I was told the waitlist for NEAD therapy was over a year."* [PT1308]

4.4.5.2 Inability to access services

Many patient and caregiver respondents commented on their inability to access services. Some struggled to access services due to appointments being cancelled or healthcare workers workload being too high:

> *"I have had 4 cancelled neurology appointments and are still awaiting further dates."* [PT1098]
>
> *"GP is very stressful experience and I avoid like the Plague! Neurologist is lovely however rarely see or hear from her due to her massive workload."* [PT1157]

Some participants mentioned how the limited time allotted for appointments affected healthcare:

> *"Limited time to treat these complex patients, who need more time than other neurological rehab patients."* [HCW1307]
>
> *"Neurologists need more time to see patients - typical neurology new patient appt is 25 minutes long."* [HCW1309]
>
> *"He was thorough in his explanation but there wasn't time for my questions and concerns."* [PT1319]

Others provided experiences of when they were declined from being able to access services:

> *"When he was diagnosed, my son was 16 and unable to access the specialist physiotherapy he needed because of his age. The doctor who delivered the diagnosis would only treat adults and we were then left to try to find someone who would/could treat him, which took another six months."* [CG1126]
>
> *"Neurologist recommended neuropsychiatry and neuro-physiotherapy. Both have been declined due to funds/criteria. No other support has been offered. No follow up is made."* [CG1160]

Several respondents explained how services were limited or non-existent in their area. This inability to access services may be due to a 'postcode lottery' (Graley et al., 2011):

> *"Neurologist and he has been brilliant but he's trying his best to provide services where there are no services in my area, so he's fighting an uphill battle too."* [PT1031]
>
> *"Got a diagnosis then just left as no treatment available due to postcode lottery NHS healthcare. Very sad and disappointed."* [PT1061]

> *"Without my boyfriend advocating for me it would never have happened. I've had to use his address in Birmingham to access support."* [PT1316]

Indeed, participants living outside of England commented on the lack of FND support available to them, with one even explaining how a healthcare worker travels from England to Scotland to support their local healthcare service:

> *"Seen my neurologist again in December, turns out he is from England and comes up to Scotland to help out."* [PT1109]
>
> *"In Ireland there is nothing even close to healthcare and services for diagnoisis [sic]."* [PT1256]
>
> *"Treatment seems to depend on Region. In Dundee Scotland help is poor/ non-existent."* [PT1267]
>
> *"Resident in Jersey...Would be good to see a specialist, but who?"* [CG1174]

4.4.5.3 Resource waste

Resource waste was a major point when commenting on resources provided by health services. Some patient respondents felt that they were wasting healthcare workers time by accessing services. Surprisingly, a small number of caregivers and patients explained how they felt that their experience of the diagnostic and treatment processes for FND was an *"utter waste of time"* [PT1011] or an overuse of resources:

> *"My neurologist was very patronising, would not let me speak, told me "there is nothing wrong with you, you are wasting NHS money"."* [PT1187]
>
> *"I found the whole process insulting, ridiculous and a complete waste of NHS resources. My husband was offered CBT and exercise. He's already had CBT- prior to FND diagnosis, and exercise is out of the question"* [CG1233]
>
> *"Most neurologists were supportive, though I felt like I was getting the same tests (bloods, MRIs) multiple times when it was unnecessary"* [PT1319]

Although resource use is an issue in most healthcare services, it is pertinent to discuss the experiences of resources reported by survey respondents. Participants explained how they were unable to access healthcare, due to lengthy waiting lists or because of the postcode lottery where services were unavailable in their location. This lack of access is a major issue for patients with an FND diagnosis, as it has been reported that FND patients who face delays in diagnosis and treatment are more likely to have poorer clinical outcomes (O'Keeffe et al., 2021).

4.4.6 Theme 6: Diagnosis

Respondents were asked multiple questions on the diagnostic processes for FND, including their experiences and perspectives of accessing diagnostic services, and information on which tests were undertaken to assist in the FND diagnosis, were derived from the responses.

4.4.6.1 Experiences of diagnostic testing

Patients and caregivers provided detailed responses in describing their experiences of the diagnostic process. Some explained how they were diagnosed using the rule-out approach or would have preferred healthcare workers utilising this approach. This is surprising as recent diagnostic manuals now recommend the rule-in approach (American Psychiatric Association, 2013):

> *"Needed to make sure there was no damage going on in my brain, like with MS or Parkinson's. Had to rule-out those conditions in order to believe it was FND."* [PT1031]
>
> *"I would have liked to have had an MRI, nerve conduction studies etc to rule-out/confirm the cond. [sic]."* [PT1087]
>
> *"The doctors were very good with me, neurologist was outstanding although felt I needed more diagnostic tests to rule-out other conditions."* [PT1158]
>
> *"Very slow initially as unsure whether my first seizure (tonic clonic) was an hypoxic, so had to wear a cardiogram for two days to rule-out."* [PT1244]

Other respondents commented on the ease of being able to access diagnostic services, with some experiencing little to no pushback on being referred to services, whereas others had difficulty in accessing diagnostic tests:

> *"Easy to access GP, they ordered a lot of tests and referred me to Neurology."* [PT1058]
>
> *"It was difficult because of covid. Many of the tests were given after a fight. The neurologist was very against doing them."* [CG1211]
>
> *"My rheumatologist has been fantastic and referred me to several services which lead to diagnosis."* [PT1147]

A small number of patient respondents reported that since receiving their FND diagnosis, they have struggled to receive care for non-FND symptoms. Worryingly, participants commented that they no longer disclose their FND symptoms to healthcare workers, potential causing themselves harm if given inappropriate treatment or support:

> *"I have most of the time stopped saying I have FND as any issues/ailments are then always FND related and I'm 100% of the time dismissed."* [PT1218]
>
> *"Not all symptoms reported after an FND diagnosis should just be put down to FND and if a doctor suspects FND they should be required to check if there's a treatable underlying cause."* [PT1151]

4.4.6.2 Misdiagnosis

Several patient respondents provided their perspectives of either being misdiagnosed with FND or being misdiagnosed with another condition. Respondents commented that they do not believe in their FND diagnosis, with some stating that they even went to private services for further diagnostic tests:

> *"I was told I coukd [sic] call my FND CFS/ME as there [sic] the same made up condition, by a second neurologist when I asked for a second opinion…I also seen [sic] a geneticist who said I had Ehlers Danlose [sic] Syndrome…both the private neurologist and geneticist disputed my FNF [sic] diagnosis."* [PT1143]
>
> *"Since being diagnosed I have found out (privately) that I have hypoandrogenism, hypothyroidism and NAFLD. But my symptoms such as "fatigue" were written off as purely psychosomatic without any NHS blood tests."* [PT1020]

Other patients described how they were given a misdiagnosis of another condition, leading to their symptoms worsening, or even becoming unwell due to being prescribed unnecessary medication:

> *"Was placed on anti-epileptic drugs which made me severely unwell, was told to stay on them until next neurology appointment."* [PT1070]
>
> *"GP originally dismissed symptoms as vertigo. When they worsened GP tested reflexes and sent me to MAU. MAU medical consultant did not know what caused leg weakness so referred me to neurologist as urgent case."* [PT1297]

Lastly, patient respondents provided information on whether they accept their FND diagnosis. Some reported accepting the diagnosis, while others stated they would not have struggled with the diagnosis if they were provided with more FND-specific information:

> *"I would have felt better if I had received a proper patient information leaflet about FND explaining it and showing help options/ groups available. That way I would have felt like it was an acknowledged and real diagnosis."* [PT1073]

> *"…I think once you get your head around what it is. And realise you control it, it doesn't control you."* [PT1023]

A minority of patients discussed how they have struggled to accept (or not accept) their FND diagnosis, due to appointments being rushed or suspicions of being given a diagnosis so they could be discharged from the service:

> *"I felt it was an easy diagnosis to give me to get me off the list in neurology."* [PT1102]

> *"I don't believe my diagnosis, not taking other symptoms into account. Just been left with a diagnosis of FND, don't really understand it. Don't have mental health issues, yet this is classed as a mental health illness, does not make sense to me!"* [PT1012]

> *"I felt it was rushed and not accurate enough. I have not had any follow up or check-up related to my FND in 6 years. At this point I do not trust my previous diagnosis and personally disregard it."* [PT1274]

It appears that the experiences of the diagnostic processes for FND varied widely between patient respondents, with some undergoing tests to 'rule-out' other conditions, and others feeling that enough diagnostic tests were completed to accurately diagnosis them with FND. Further, some FND patients believed they were misdiagnosed or refused to accept their FND diagnosis, including a small number who sought further private tests to confirm their condition.

4.5 Discussion

This study used both quantitative- and qualitative-based questions to identify and map the diagnostic tools and treatment options currently being implemented across UK healthcare services. It also explored the experiences of patients, healthcare workers and caregivers on the diagnosis and treatment of FND.

The implications of this chapter are presented in relation to the study's research aims and objectives. The survey results have been compared to the findings from the scoping review (Chapter 2) and recommendations for the clinical management of FND have been considered.

Before moving on to discussing the findings from each study objective, it would be prudent to present the main findings from each population group.

While patient participants provided experiences of a range of topics relating to FND and its clinical management in UK services, the main finding from their responses related to support from both healthcare workers and health services. Although some patients did have positive experiences when receiving support from healthcare workers, most were predominantly negative. Patients expressed how they were left feeling anxious, frightened or embarrassed from their interactions with healthcare workers. Patients frequently experienced dismissive behaviour or a lack of compassion and empathy during appointments, with some even facing accusations of malingering. Interactions with healthcare workers led to many patients feeling unsupported and ignored, either due to a lack of communication, attitudes or FND-specific knowledge. These views were supported by caregiver respondents, who reported that healthcare workers provided little support to FND patients and were frequently dismissive. This corroboration is not surprising as caregivers would have likely been present during medical appointments and witnessed these interactions first-hand. While healthcare worker respondents were clear in their descriptions of how they, as individuals, provide high-quality care, they did not discuss in detail the views of other healthcare workers in their own service. Interestingly, healthcare worker respondents commented that FND patients *“take up a lot of [their] time”* [HCW1307], which is perhaps a possible reason for why healthcare workers in wider services struggle to provide suitable support.

FND-specific education was the main focus of healthcare worker respondents. Worryingly, only one quarter of respondents agreed the FND training they received was sufficient. While some acknowledged that this lack of formal education was due to FND not being recognised as a health condition during their clinical training, only a handful of the respondents who had recently completed their medical degree or speciality training had received FND-specific education. This lack of FND-specific training negatively impacted the knowledge and confidence of healthcare workers involved in the clinical management of FND. Although most healthcare worker respondents felt they were moderately knowledgeable about FND, less than 25% felt ‘very knowledgeable’. This opinion had a knock-on effect on patients, as they faced delays when accessing services, as healthcare workers were unsure of the steps to clinically manage the condition.

These findings were corroborated by both patient and caregiver respondents. Respondents noted the lack of healthcare worker knowledge during FND diagnostic and treatment appointments, stating that only a minority understood the condition and were able to provide sufficient information. All population groups discussed the need for specific FND education and training for healthcare workers.

Lastly, the negative impact of providing support was the main finding derived from the caregiver respondents. The complexity and quantity of care duties when providing support led to caregivers feeling emotional and overwhelmed, especially since they often found themselves not having enough time to complete these tasks and meet their own needs (whether personal needs or employment needs). While noting that professional support needed to be put in place so the person they support can be suitably cared for, many caregivers were unable to access support for themselves. This lack of support perhaps led to caregivers feeling more overwhelmed and burdened by their caregiving duties.

Caregiving duties negatively impacted caregivers both financially (due to having to take time away from work to provide support or even having to leave employment) and socially; some reported feeling socially isolated or suffered from friendship and relationship breakdowns, as they only had limited time available to spend away from their caregiving duties. Although the other population groups did not provide comments on the negative impact of caregiving, patient respondents did acknowledge the negative impact of their FND symptoms on their family and loved ones.

4.5.1 Service mapping

One of the objectives of this survey study was to map the current FND diagnostic tests and treatments currently being used in UK services. Diagnostic tools and treatment data were reported by 309 participants located across 22 UK regions. The main diagnostic test (reported across all regions) were neurological examinations, and the most common treatment intervention reported was physiotherapy. The most common diagnostic tool finding is consistent with the scoping review (Chapter 2), which found that neurological examinations were the most reported diagnostic tools in relevant articles.

In terms of diagnostic tests and location, patients based in England were most likely to receive MRI scans, whereas patients located in Wales or Scotland were equally as likely to receive blood tests or MRI scans. Regarding treatment options, patients in England were more likely to receive physiotherapy, whereas patients in Scotland were more likely to be prescribed medication, while patients in Wales were more likely to receive CBT or medication. Unfortunately, only a limited amount of data were collected on the clinical management of FND in Northern Ireland, therefore diagnostic and treatment information could not be mapped.

4.5.2 Diagnostic processes

Respondents were asked a range of questions on the diagnostic tools used in UK services, and their experiences of receiving an FND diagnosis (if applicable). Patients were asked to report the duration from when they first reported their symptoms up to diagnosis. Over one third of patients (n = 91; 35.4%) reported receiving their diagnosis between 0 and 6 months. This was supported by healthcare worker respondents who are directly involved in FND diagnostic processes, with 60% (n = 6) also reporting 0 and 6 months. Services with the shortest referral time included community and acute stroke services, persistent physical symptoms services, neurology services and acute hospital services (0 and 6 months). General practice was reported as the longest, taking between 19 and 24 months to receive a referral.

Neurology was the service most visited by patients (n = 167). Accident and Emergency and GP offices were the next most visited services (n = 116 and n = 116, respectively). The most reported diagnostic tests reported by patients and caregivers included neurological examinations (n = 181), MRI scans (n = 158), blood tests (n = 152), positive clinical signs (n = 94), EEG tests (n = 90) and CT scans (n = 72). The diagnostic tests reported in this study are consistent with those reported in the scoping review (Chapter 2), indicating that services are following evidence-based research when supporting patients.

Healthcare worker respondents were asked to report which assessments they have used (or assisted in) during the past two years to diagnose FND, as well as which assessments they think are necessary to establish an FND diagnosis. Interestingly, fewer healthcare workers believed that positive clinical signs were necessary when diagnosing FND than those who used them (n = 10 and n = 11, respectively). This is a surprising finding, as the evidence base for positive clinical signs provided in the scoping review demonstrate a high specificity and sensitivity. Unfortunately, from the data collected, it is not possible to determine why there is a lack of belief. Some possibilities include a lack of confidence in the diagnostic tool, or if healthcare workers lack confidence in using positive clinical signs as a diagnostic method. Some diagnostic tools were reported to be necessary but rarely used (such as fMRI, vEEG and VEM). These tools may only be used sparingly due to cost or a lack of technology in services.

The experiences of the diagnostic process differed greatly between patient and healthcare worker respondents. Many patient respondents reported negative experiences, such as where they faced negative attitudes or were dismissed by healthcare workers. Indeed, many felt that healthcare workers did not believe them or suspected they were feigning their symptoms. Healthcare workers not providing enough FND-specific information was also described. This contrasts healthcare worker experiences, with many reporting that their service is suitable for diagnosing FND patients, and that their service has well trained staff members who provide education and support to patients.

Fascinatingly, several patients reported that they believed they were misdiagnosed with FND, and some did not accept their diagnosis. This lack of acceptance may be due to the negative attitudes experienced during the diagnostic process. It has been reported that negative attitudes from healthcare workers impact on patients; patients who experience these attitudes are less likely to accept the FND diagnosis and engage with treatments (Fouche et al., 2019, Rawlings et al., 2017).

4.5.3 Treatment processes

Participants were surveyed on the current available treatments for FND. The main treatments reported by patients and caregivers included medication (n = 92), physiotherapy (n = 86), cognitive behavioural therapy (CBT; n = 53), occupational therapy (n = 46) and educational websites (n = 35). Healthcare workers directly involved in FND treatment processes (n = 19) reported similar treatment options, with occupational therapy (n = 11), physiotherapy (n = 11), CBT (n = 11) psychoeducation (n = 10 and medication (n = 10) being the main treatment options provided by their service. These treatment options map on to the scoping review findings that medication and psychological therapies were the most reported interventions in the evidence base.

Patients were asked to report the duration of any treatment they were undergoing/had received, and whether they felt the treatments improved their FND symptoms. Over one third of those who had received physiotherapy (n = 27) felt that it helped reduce symptom severity and nearly one quarter (n = 17) of the patients prescribed medication felt that medication reduced their FND symptoms. Lastly, only 15 patients receiving CBT felt it reduced their symptoms. These findings are quite remarkable as these well-evidenced treatment options are only having a useful effect on a small number of patients undertaking them.

Similar to the diagnostic processes, healthcare worker respondents were asked to report which FND treatments should be offered by health services. Healthcare worker respondents stated that all treatments except medication should be offered, however the treatments are not being offered widely across services. This may be due to FND clinical guidelines from other countries (as currently there are no NICE FND guidelines) recommending psychological therapy over medication for FND.

All healthcare workers (n = 19) directly involved in FND treatment processes reported that the treatment(s) offered by their service were effective. However, when including all healthcare worker responses to this question, three responded negatively, When asked to explain their thoughts, the main reason for this ineffectiveness was due to a lack of resources available to meet demand. Respondents commented on the lack of FND specific services in their location, or time restrictions and communication breakdown between teams that caused treatments to be less effective. Resource use is further discussed in Section 6.3.

All respondents were surveyed on shared decision-making processes when deciding on treatment options. Respondents who agreed that shared decision-making occurred between patients and healthcare workers reflected on effective communication and collaboration. However, patients who disagreed that shared decision-making occurred, disclosed that they did not feel involved and that decisions were *“out of their hands”* [PT1086]. It is concerning that patients do not feel that shared decision-making is occurring, as it is heavily encouraged in international clinical guidelines in order to improve patient engagement and clinical outcomes (GGZ Standaarden, 2021).

4.5.4 Patient needs during the clinical management of FND

One of the study’s objectives was to identify patient needs when accessing services. Patients were asked for their perspective on what services could do differently to improve the experiences of those undergoing the clinical management of FND, with many focusing on more compassion, communication and knowledge from healthcare workers, as well as more resources being put in place to support them. Patients felt that healthcare workers did not show compassion or empathy, were dismissive of their symptoms, or were not supportive. In addition, patients commented on the possibility of seeing the same healthcare workers during the diagnostic process, and having follow-up appointments after receiving their FND diagnosis. While expressing a want for continuity of care, patients reflected on how their experiences of healthcare services had led them to lose trust, and how they may refuse to access services in the future. These points highlight the importance of healthcare workers regaining and building both trust and rapport, in order to develop the patient-healthcare worker relationship, as a strong patient-healthcare worker relationship improves the likelihood of the patient accepting their diagnosis and improves patient outcomes (Fouche et al., 2019, Rawlings et al., 2017).

Although healthcare workers expressed that their service does offer support to FND patients (such as signposting to organisations and providing information leaflets explaining the condition), patients did not wish to engage with the support available. This could possibly be because information from signposting and leaflets is passive, or that patients may not have the energy to be proactive in engaging with the organisations to which they are signposted, or to read information leaflets. When asked how support could be improved, patients acknowledged needing and wanting more active support and wanting to make connections (such as accessing peer support groups or outside organisations and charities). This may be due to wanting to share their experiences with others who have lived experience of FND and may likely understand their perspectives better than those without this experience.

4.5.5 Strengths and limitations

This study utilised a mixed-methods approach to gather evidence in order to answer the research aims and objectives. The questions were derived from the up-to-date evidence provided in the scoping review (Chapter 2) and the questions were piloted by public and patient involvement representatives to ensure they were relevant, clear and accessible.

In order to ensure the study was as accessible as possible, participants were given the option to complete the survey over the phone, via videoconference or by post. All participants completed the survey independently online.

The study had a high patient recruitment number, but ultimately this caused an imbalance between patient, caregiver and healthcare worker recruitment numbers. A lot of effort was put into recruiting healthcare workers, with 28 completing the survey. In addition, the survey narrowly missed the target recruitment figure for caregivers (n=35), as 34 completed the survey. Recruitment is geographically representative and also representative of reported FND symptoms. However, a small number of regions were unable to be mapped due to a low number of participants from specific regions.

Recruitment occurred online due to limitations imposed by the COVID-19 pandemic. However, the recruitment strategy was as inclusive as possible in order to reach many potential participants. A range of patient and caregiver support groups (and organisations) were contacted to share the study, and healthcare worker groups and organisations were also contacted. However, as the study was predominantly shared on social media platforms, there is a chance that not all relevant population groups would have been reached, leading to sampling bias. As the patient and caregiver experiences were predominantly negative, there is also a chance that selection bias may have affected the survey. For example, only those who had negative experiences wanted to complete the survey, whereas those who had a positive or neutral experience may have not wanted to complete the survey and share their perspectives.

The potential biases relating to the methodology used are further limitations. Response bias may have impacted the results and subsequent analysis. For example, some respondents may have tried to complete the survey as quickly as possible, leading to them not select accurate responses for their situation, or other respondents may have skipped the open response questions, not wanting to spend extra time writing out their experiences. A risk for all survey studies is demand characteristics. There is a chance that participants may have changed their answers due to their interpretation of the aims of this study, or had their own agenda. In addition, participant bias may have also skewed respondents' answers.

While each survey was structured in a logical and streamlined way, question order bias may have also skewed the results. Further, while efforts were made to ensure survey questions were clearly worded and no jargon included in the text, some may still have been unclear to participants, leading to ambiguous or complex questions and skewed responses.

4.5.6 Implications for clinical practice

This survey highlights that the clinical management for FND varies across the UK, as different diagnostic tests and treatments are offered in services depending on its geographic location. In addition, it appears that there are lengthy delays in patients accessing diagnostic and treatment services, with some patients having to wait over five years to receive their FND diagnosis. While these delays may be due to limited resources and budget cuts to services, it still poses a clinical challenge, as FND patients who face delays to diagnosis and treatment are more likely to experience negative clinical outcomes (O'Keeffe et al., 2021).

The lack of FND-related knowledge and FND-specific training is concerning. This lack of knowledge and training may be a contributing factor to healthcare workers' negative attitudes and stigma towards the condition. If FND patients experience negative attitudes from healthcare workers, they are less likely to accept their diagnosis and engage with services. This lack of knowledge and stigma may also be related to the lack of UK clinical guidelines currently available; healthcare workers may be unsure of where to find accurate information on the condition, or not believe the condition exists due to the lack of guidelines.

This study reveals the need for FND-specific training and education, and improvements in the communication networks between health services. Although the findings from this study highlight that healthcare workers can be very knowledgeable on the condition, training needs to be implemented into all clinical training courses, as FND patients are being treated in a wide range of services. The findings from the content analysis demonstrate how communication breaks down between services, leading to delays in diagnosis and treatment.

4.6 Conclusion

This study provides an in-depth analysis of the experiences of patients, caregivers and healthcare workers involved in the clinical management of FND in the UK. Remarkably, a large number of participants across the UK completed the study, allowing the opportunity to map services across regions located in England, Scotland, and Wales.

A wide range of experiences were reported from participants. Diagnostic tools and treatments tended to map on to the existing evidence reported in the scoping review. However, the gold standard diagnostic test (vEEG) was not well utilised in services. This may be due to the costs associated with the test, or that not all services have access to vEEG equipment.

Overwhelmingly, patients and caregivers reported instances of negative attitudes, stigma and dismissive behaviour when accessing health services. This is concerning, as these negative behaviours can have a detrimental impact on patients. This was highlighted in the findings as one patient described feeling suicidal due to their ill-treatment from healthcare workers.

This survey discovered a lack of FND specific training for healthcare workers, negatively impacting on the knowledge and confidence of those who work with, diagnose and treat FND patients. This study reflects the need for more in-depth training for healthcare workers, not only to better them, but to ensure that more healthcare workers understand that FND is a legitimate health condition, and that FND patients are deserving of a high standard of care.

Chapter 5: An interview study investigating the experiences of the diagnosis and treatment processes for Functional Neurological Disorder

The following chapter presents the findings of the interview study conducted as part of this thesis. Twenty-eight semi-structured interviews were conducted between 24th June and 15th November 2022. The interviews aimed to explore the experiences, perceptions and beliefs of UK-based patients, caregivers and healthcare workers on the clinical management of FND, including identifying potential triggers for the onset of FND.

This chapter begins by presenting the demographic data for all three population groups. This data will then be followed by a reflexive thematic analysis of the collected interview data. Respondents were asked questions relevant to their population group. The findings from the survey and interview studies have been triangulated and are presented in Chapter 6. The methods utilised for this study are presented in Chapter 3.

5.1 Study rationale

Although a small number of studies have documented the perspectives of healthcare workers on the management of FND, there is very limited evidence from patients and none from the caregivers' experience. The few studies exploring this phenomenon (Kanaan et al., 2011, O'Connell, 2017, Rawlings et al., 2017) only recruited a small sample size or focused on one setting (e.g., a neurology department), and did not involve UK-based participants. Thus, research is needed to explore the experiences (both positive and negative) of healthcare workers, patients and caregivers involved in the diagnosis, treatment and care of FND in UK health services.

5.2 Aims & Objectives

This interview study aimed to explore the experiences of healthcare workers, patients and caregivers on the diagnostic and treatment processes for FND in the UK.

The study objectives were to:

- Identify any potential triggers for the onset of FND
- Understand the diagnostic processes and treatments for FND
- Understand the attitudes and beliefs of healthcare workers working with patients diagnosed with FND

- Explore the lived experience of patients diagnosed with FND
- Understand the experiences of caregivers providing support to people with FND

5.3 Analysis

As reported in Chapter 3, it was planned that 30 interviews would be conducted to ensure a wide range of experiences were collected. In total, twenty-eight participants (10 patients, 10 healthcare workers, and 8 caregivers) were interviewed. Participants were recruited via purposive and opportunity sampling. 56 survey participants were invited to take part in the interview study (caregivers n = 20, healthcare workers n = 18, patients n = 18), with 21 deciding to take part (caregivers n = 8, healthcare workers n = 4, patients n = 9) and one caregiver declining to take part in an interview. The remaining 34 survey participants did not respond to the invitation email. Six participants (healthcare workers n = 5, patients n = 1) were recruited via word of mouth and social media (Twitter).

5.3.1 Demographic data

Participants recruited via opportunity sampling were asked five or six demographic questions relevant to their population group (healthcare workers were asked an extra question which queried the duration of which they had worked with FND patients). Demographic data were retrieved from the survey study for participants recruited via opportunity sampling (with their permission).

Of the 28 interviews completed, 23 were held over video conference (Zoom) and 5 via telephone (via Zoom teleconferencing). Interview duration differed between the three population groups, with patient interviews lasting on average of 49 minutes, caregivers 57 minutes and healthcare workers 44 minutes. 67.9% of participants (n = 19) identified as female, and 32.1% (n = 9) as male. Age brackets were used to protect the anonymity of participants, with 3 (10.71%) aged between 25-34 years, 8 (28.57%) aged between 35-44 years, 5 (17.86%) aged between 45-54 years, 9 (32.14%) aged between 55-64 years, and 2 (7.14%) aged between 65-74 years. Two-thirds of the participants stated their ethnicity as White British (67.9%; n = 19). Lastly, participants were recruited from all four constituent countries across the UK, with the majority based in England (67.9%; n = 19). Table 41 below provides a breakdown of the demographic information. As there are only a limited number of healthcare workers who work in FND settings, age brackets, ethnicity and location have not been reported to ensure participants remain anonymous.

Table 41: Demographic information

Respondent type	Gender	Age	Ethnicity	Geographic Area	FND diagnosis	Relationship with patient	Duration of caregiving	Job title	Years worked with FND patients	No. of FND patients seen per year
Caregiver respondent information										
Caregiver 1 (CG1)	Female	45-54	White British	England		Parent/ Parent-in-law/ Guardian	2-5 years			
Caregiver 2 (CG2)	Female	55-64	White British	England		Spouse/ Partner	6-12 months			
Caregiver 3 (CG3)	Female	55-64	White British	England		Spouse/ Partner	Over 5 years			
Caregiver 4 (CG4)	Female	35-44	White British	England		Parent/ Parent-in-law/ Guardian	6-12 months			

Respondent type	Gender	Age	Ethnicity	Geographic Area	FND diagnosis	Relationship with patient	Duration of caregiving	Job title	Years worked with FND patients	No. of FND patients seen per year
Caregiver 5 (CG5)	Female	55-64	Prefer not to say	Wales		Spouse/ Partner	Over 5 years			
Caregiver 6 (CG6)	Female	55-64	White British	Wales		Parent/ Parent-in-law/ Guardian	Over 5 years			
Caregiver 7 (CG7)	Female	35-44	Prefer not to say	England		Parent/ Parent-in-law/ Guardian	1-2 years			
Caregiver 8 (CG8)	Male	65-74	Prefer not to say	England		Parent/ Parent-in-law/ Guardian	Over 5 years			

Respondent type	Gender	Age	Ethnicity	Geographic Area	FND diagnosis	Relationship with patient	Duration of caregiving	Job title	Years worked with FND patients	No. of FND patients seen per year
Healthcare worker respondent information										
Healthcare worker 1 (HCW1)	Male			England				Clinical psychologist	Over 20	41-50
Healthcare worker 2 (HCW2)	Female			England				Nurse	6-10	6-10
Healthcare worker 3 (HCW3)	Female			England				Principal clinical psychologist	6-10	31-40
Healthcare worker 4 (HCW4)	Male			Scotland				Consultant chemical pathologist	0-5	0-5

Respondent type	Gender	Age	Ethnicity	Geographic Area	FND diagnosis	Relationship with patient	Duration of caregiving	Job title	Years worked with FND patients	No. of FND patients seen per year
Healthcare worker 5 (HCW5)	Male			England				Neurological physiotherapist	0-5	>100
Healthcare worker 6 (HCW6)	Female			England				Rehabilitation practitioner	0-5	20
Healthcare worker 7 (HCW7)	Female			England				Clinical lead speech and language therapist	Over 20	3-4
Healthcare worker 8 (HCW8)	Female			Wales				Speech and language therapist	0-5	3

Respondent type	Gender	Age	Ethnicity	Geographic Area	FND diagnosis	Relationship with patient	Duration of caregiving	Job title	Years worked with FND patients	No. of FND patients seen per year
Healthcare worker 9 (HCW9)	Male			England				Consultant neurologist	11-15	400
Healthcare worker 10 (HCW10)	Female			England				Consultant stroke physician	0-5	100-200
Patient respondent information										
Patient 1 (PT1)	Female	35-44	White British	England	FND, FMD					
Patient 2 (PT2)	Male	55-64	White British	England	FND					
Patient 3 (PT3)	Female	45-54	White British	Scotland	FND					

Respondent type	Gender	Age	Ethnicity	Geographic Area	FND diagnosis	Relationship with patient	Duration of caregiving	Job title	Years worked with FND patients	No. of FND patients seen per year
Patient 4 (PT4)	Male	35-44	White British	Northern Ireland	FND					
Patient 5 (PT5)	Male	55-64	White British	England	FND					
Patient 6 (PT6)	Female	25-34	Black - African	England	FS					
Patient 7 (PT7)	Female	65-74	White British	Wales	FND, FMD					
Patient 8 (PT8)	Male	55-64	White - any other white background	Scotland	FNSD					
Patient 9 (PT9)	Female	55-64	White British	England	FND, FS					

Respondent type	Gender	Age	Ethnicity	Geographic Area	FND diagnosis	Relationship with patient	Duration of caregiving	Job title	Years worked with FND patients	No. of FND patients seen per year
Patient 10 (PT10)	Female	35-44	Mixed race - white and black Caribbean	England	FND					

FMD = functional movement disorder; FND = functional neurological disorder; FNSD = functional neurological symptom disorder; FS = functional seizures.

5.3.2 Potential triggers for the onset of FND

One objective of this study was to identify the potential triggers for the onset of FND. As discussed in Section 1.4, there has been much speculation on the aetiology of FND, yet to date, a firm reason has not been identified. All interview participants were asked for their perspectives on the potential triggers for the onset of FND and provided a wide variety of opinions. Patients and caregivers reflected on their own reasons why they (or the person they support) may have developed FND, whereas healthcare workers provided a more general overview. Although most provided definite reasons for the onset of FND, some participants explained how at times, the trigger *"can be absolutely anything"* [HCW5] and the narrative surrounding the trigger is almost *"always more complex"* [HCW9]:

> *"I do think it's obviously the experience that goes with this and often, sort of the uncertainty. So if somebody thinks that they…if somebody believes that they are really threatened or they're going to, they really need to protect a limb or a body part or something or they're really unwell. I think the emotional and the psychosocial kind of result of having an illness or physical injury can often be the main problem. So the trigger might be, 'I fell over and banged my head', but then I might think that I've got internal bleeding or that I am going to have to go to hospital or that I'm going to have to take a week off work and I won't get paid. And then all that uncertainty, I think combined with the physical trigger, can then develop…lead on to development of a functional symptom."* [HCW5]

Potential triggers for the onset of FND included stress, COVID-19, trauma and physiology. Table 42 provides a breakdown of the potential reasons for the onset of FND as reported by interview participants.

Table 42: Reported reasons for FND onset

Potential trigger	**n(%)**	**Participant comments**
Mental health issues/ trauma	15 (53.6%)	*"I think that it can be triggered with a traumatic event."* [PT3]
Physiological issues/ physical trauma	14 (50%)	*"It's a terribly long story! In 2009 I had a life-threatening pericarditis. And it all stemmed from that."* [PT3] *"With me, um, I had spinal cord compression in my neck."* [PT4]
Stress/life stressors	9 (32.1%)	*"A key theory seems to be a stress trigger, and he has had a lot of stressful events in the last five years, such as getting divorced, losing a parent, losing a job he loved. And all that is sort of condensed."* [CG3] *"And I know, it was things like…so as I was doing my own practice and teaching, I was teaching over a period a week, and weekend teaching as well. So it's just doing too much…But on top of that was the other things that were coming, everyone was lost, I had lost control, basically."* [PT9]
Emotional problems/ issues	6 (21.4%)	*"For some people, you do see the more conventional response to a life event, emotional trigger."* [HCW1]
Vaccination	4 (14.3%)	*"The only thing with him is before both events, with one with his walking and the other with his speech, he had not long had his COVID vaccinations, and we wondered whether it could be anything to do with that."* [CG2]
Autism	3 (10.8%)	*"I'm gonna go out on a limb and say not being diagnosed as autistic as a young person. I don't know if you've heard that before. But I think that she's on the autistic spectrum and it was missed."* [CG6]

Potential trigger	**n(%)**	**Participant comments**
COVID-19	3 (10.8%)	*"As a result of COVID. In 2020…March 2020, I came down with COVID. Before that I was fit and healthy."* [PT5]
PTSD	3 (10.8%)	*"Um, so for [name redacted], it was a post-traumatic stress reaction. We were going through a very bad time, um and he came out with FND!"* [CG1]
Iatrogenic harm/medication	2 (7.1%)	*"Well, very much as a result of having taken an antidepressant, an SSRI antidepressant."* [PT7]
Viral infection	2 (7.1%)	*"And that she also triggered by tonsillitis, it triggers it. She's had tonsillitis every month for over a year. And whenever she gets tonsillitis, her symptoms just get really bad. She's never really tonsillitis before getting the condition either."* [CG4] *"In my case, it's almost certainly post viral."* [PT8]
Genetics	1 (3.6%)	*"I think there might be a genetic link."* [HCW2]

5.3.3 Reflexive thematic analysis

As detailed in Chapter 3, the principles of reflexive thematic analysis set out by Braun and Clarke (2019; 2022) were followed. Using these principles, five themes (each containing several sub-themes) were generated. Each theme and sub-theme are presented in Table 43. Each theme is outlined below, using quotes from the interviews to exemplify the findings. A description of each theme and sub-theme can be found in Appendix 12 and a table showing how each participant contributed to the presented themes can be found in Appendix 17.

Table 43: Summary of generated themes and sub-themes

Theme	Sub-theme	Codes	Codes
Support: ‘it takes a village’	Support received from healthcare workers	Healthcare worker attitudes and behaviours	Changes in behaviour and attitudes
			Dismissive behaviour
			Negative attitudes
		Interest and willingness to work with FND patients	Awareness of FND
		Knowledge and expertise	Confidence
			Knowledge of FND
			Misdiagnosis
	Support from the community	Peer support	Social media
			Support groups
		Support from friends	
	Support from caregivers	Advocacy	
		Caregiver involvement	
	Support from family and loved ones	Ability to provide support	

Theme	**Sub-theme**	**Codes**	**Codes**
	Support from school and work	Willingness to support patients and caregivers	
The art of communication	The patient-healthcare worker relationship	Shared decision-making	
		Understanding	Empathy
			Listening
			Rapport building
	Information sharing	Communication styles	Ability to adapt language
			Analogies
			Clear information
		Information searching	
		Signposting	
	Communication between healthcare workers and services	Collaboration	
Resources: the barrier to effective and timely care	Waiting times	Accessing private care	
		Differences in waiting times	
		Falling through the cracks	

Theme	Sub-theme	Codes	Codes
	Barriers to accessing resources	Continuity of care	Passed pillar to post
		Postcode lottery	
		Multidisciplinary teams	
Life after diagnosis	Adapting to the new normal	Adaptations to the home	
		Learning to live with FND	Different mindsets
		Personality changes	
	Treatments: the road to nowhere	Access to treatments	Self-management
		Avoiding accessing healthcare	
		Readiness for treatment	
	Accepting and believing the ‘FND label’		
The impact of functional neurological disorder	FNDs impact on the self	Independence	Inability to complete everyday tasks
			Isolation
			Missing school or work

Theme	Sub-theme	Codes	Codes
		Physical health impact	
		Mental health impact	
		Unpredictability of symptoms	Preparing for the unpredictable
		Livelihood	Loss of livelihood
		Finances	Accessing benefits
			Loss of income
	FNDs impact on the family unit	Changes to the family dynamic	
		Impact on children	Resilience
	Impact on friendships	Avoiding conversations	
		Evaluating friendships	Fair-weather friends
	FNDs Impact on healthcare workers	Pressure felt by healthcare workers	

5.3.3.1 Theme 1: Support: ‘it takes a village’

The first theme of this study highlights how a whole ‘village’ is needed to support a patient undergoing their FND diagnosis and beyond. It has been reported that social engagement and support from proximal (such as family members or close friends) or distal individuals (those who are outside of a person’s family or close friendship circle, for example, a healthcare worker or a professional from a charitable organisation) not only have a positive impact on a person’s quality of life, but also improves mental wellbeing (Graziani et al., 2022). The support received from proximal and distal individuals (and groups) were reflected on by participants throughout the interviews.

5.3.3.1.1 ‘Support’ received from healthcare workers

Participants perceived that healthcare workers were an integral part of the ‘village’ FND patients needed, when they were being supported while undergoing diagnostic tests, subsequent follow-up appointments and treatments. Participants discussed a wide range of experiences from their times of interacting with healthcare workers (or from the healthcare worker perspectives, hearing patients disclose these experiences and then relaying them to the author during their interview). They focused on how attitudes, knowledge or expertise, interest and curiosity determined the level of care and support the patient felt they had received.

After exploring previous evidence (McWhirter et al., 2011, Rawlings et al., 2017), as well as findings from the survey study (Chapter 4), it is not surprising that most patient and caregiver participants experienced negative attitudes and dismissive behaviours. One participant reflected on how these negative experiences may be due to the beliefs of the healthcare workers:

> *“I don't use them very much. But I do feel they believe me. I think that's the barrier, isn't it?”* [PT9]

This lack of belief in the condition, or that FND patients were *“malingering”* [CG5], led to many patients being treated poorly by healthcare workers. Patients experienced a change in attitude (from positive to negative) when it was first believed they had another health condition (such as epilepsy or stroke). This change in attitude from healthcare workers may possibly derive from believing the symptoms the patient is experiencing are caused by an organic condition, therefore the condition may typically be diagnosed via standardised and validated assessment tools. However, when these organic conditions have been ruled-out, healthcare workers who do not have an understanding of FND may then believe that the patient is malingering, and their attitude towards the patient becomes negative.

Patients who had experienced negative attitudes began to doubt that their own FND symptoms were real, or became reluctant to report their FND diagnosis in future clinical appointments as they felt they would not be believed or would be further accused of malingering:

> *“But it has left a lasting legacy with [husband] because he still doubts himself now and he shouldn't have to, you know, with everything else is going on…every now and then he’ll say, ‘I'm faking it, aren’t I, because she said I was’, you know, so that's awful. That is awful.”* [CG5]

> *“But generally, you'll find that it won't be the first thing that I tell them [healthcare workers], because…they also get oh… what's the word? They can sometimes treat you differently if you say you’ve got FND. Of course, it didn't used to be believed as an illness. So now, at any point if I'm not well, I would do my utmost to not end up in hospital because of that situation.”* [PT3]

Negative attitudes and dismissive behaviour appeared to go together during the diagnostic process. Healthcare workers reflected that although they had a *“good attitude”* [HCW2] towards the clinical management of FND and wanted to support FND patients, they were aware of *“flippant”* [HCW2] or “*old school”* [HCW3] attitudes that patients experienced from healthcare workers in other services:

> *“So I like to think that my clinicians are very good at treating people and have good attitudes. However, every single patient that I've come across…the worst attitudes come from neurologists, I think. So I… they are very, very flippant in their diagnosis…I think every single patient that I've touched base with that has seen a neurologist spends about the first 20 minutes with me really, really angry that they've been treated that way, and that they've been treated dismissively. And, you know, the phrase, ‘it's all in your head’ is still used. I currently have a stroke consultant who is quite good at diagnosing FND but he does straight referrals to mental health for everybody. You know, and not everybody needs to see somebody in mental health, so then they're already made to feel that they're a bit of a lunatic, you know.”* [HCW2]

> *“Um, I think it's kind of…I guess, it's like in lots of services, really, it's quite a mixture of different approaches and attitudes. I think probably, more times it varies with*

> *people's upstream experiences of diagnosis and that side of things. In the early days, we did get quite a few people who just came to come and shout at us, but I think that was particularly about a specific experience with one very old school neurologist who they've seen! Who I think, fortunately for everybody, has since retired!"* [HCW3]

These attitudes, or culture of disbelief in FND, may stem from conversations with senior healthcare workers during medical training, or from not having an understanding of the disorder. Indeed, multiple healthcare workers (and even one patient who was employed by an NHS Trust) stated that they had heard recently qualified or locum healthcare workers discuss how FND is not a real condition, as they were told so by the person training them.

While many patients experienced dismissive and stigmatised attitudes from healthcare workers, some used these experiences as motivation *"to prove [the healthcare workers] wrong"* [PT1] and continue with their education or career. As well as perceiving that they were treated differently (due to their FND diagnosis), patients reflected on how their race and/or gender impacted on the healthcare worker attitudes. Two female patients (one African, one White British) discussed how they were treated differently, with one hypothesising that if she were a man, or if FND was more of a male-dominant condition, there would be more treatment options or even a cure. Although at the time of writing there is no published information on ethnicity disparities in FND care, a recent publication has highlighted how conditions (which primarily affect women) are neglected in clinical research and healthcare priorities; it calls for FND to be recognised as a feminist issue (McLoughlin et al., 2023). These thoughts were enforced by a male patient, who was told by a consultant doctor that FND is just a *"psychiatric condition seen in hysterical women"* [PT8]:

> *"I just think the whole stress thing is outrageous, because it's mostly women that have this. And I'm sorry, but if men who were in stressful jobs, high powered men were collapsing to the floor and having convulsions for twenty minutes, there'd be a cure. There'd be a cure now. We'd all know exactly what this was. The way I've been treated because I'm a black woman as well. It's next level, you know. 'You can walk', I've been told that a million times. 'You can walk', 'There's nothing physically wrong with you'."* [PT6]

> *"…I was just so scared. And so I asked to see this particular [doctor] who had this particular experience. Yeah. And that was a really, really unpleasant session, really,*

> *because he, you know, he just pulled out the letters that he got from the previous ones and flipped through them, and I told him a bit what happened and I was upset. I made the mistake probably of crying. You know, as a woman you should never cry in front of the doctor because that means that you're neurotic. And, you know, I was crying because I've got this terrible movement disorder, not because there's anything wrong with me psychologically, you know! If you jerked like I did you cry too! And he just said, 'no, no, I agree. It's because of your anxiety that you have this problem. It's definitely FND'. There we are, £200 and off I go. It was just awful, honestly."* [PT7]

Healthcare worker attitudes, interest in FND and a willingness to work with (and support) FND patients were interconnected throughout the interviews. Healthcare worker respondents spoke at length of their *"passion"* [HCW6] of supporting FND patients, even going to extreme lengths by supporting patients they were not meant to see within their service. When describing their perspectives on supporting FND patients throughout the clinical management for FND, healthcare workers reflected on the sadness and frustration they felt towards their peers who had little interest in supporting FND patients, or potentially did not feel comfortable working with this patient group. Interestingly, one patient used humour to describe this lack of interest, comparing it to being placed in *"Room 101"* [PT9]:

> *"Well, strictly speaking…I'm not meant to see these patients at all. So my service is purely for stroke. But I have flagged this up as a major issue…these patients are not given any support because everybody passes them on…I do see patients because if somebody is asking for my help and support, I will give it, I just don't tell anybody I'm doing it! [laughs]."* [HCW2]

> *"…I went off on parental leave from December to June…and in that six-month period when I was off, the referrals to our specialist FND service dropped off dramatically. Because within our team, I am known as 'the FND one'. I'm the one who may potentially feel more comfortable diagnosing it, thinks about it more routinely, doesn't necessarily go looking for the other diagnosis."* [HCW10]

> *"…I don't genuinely think they're just trying to get rid of people or get them off the books or whatever. I think it's just a lack of understanding and a lack of maybe, a lack of openness to consider a new condition like and a lack of curiosity to actually investigate what's actually going on."* [HCW4]

The experiences and perspectives of patients (on the apparent interest of healthcare workers regarding FND and supporting the patient) were widely discussed. Patients reflected on how they were surprised at how little interest the assigned healthcare worker showed in their condition, finding that they *"couldn't be bothered"* [CG4], yet the healthcare worker's peer was *"fascinated* [and] *wanted to know everything about it"* [CG4]. As FND is a relatively unknown health condition, when cases arise in hospital it may pique the curiosity of junior and senior healthcare workers alike, and be seen as a good teaching opportunity for medical students. In contrast, another patient spoke bitterly about the interest shown to them, due to them having to live with the condition:

> *"…I thought that the neurologists would be curious and go, 'Oh, this is really interesting what's happening to you. You know, I'm a neurologist, I want to know, I want to know what's going on in your nervous system'."* [PT7]

> *"…people will say to me, 'well, what's happened to you is really interesting and it's very complicated'. And I'll go 'Well yeah, I know, but I've got to live it!' But it is interesting, you know, I've always had lots of students around my bed in hospital."* [PT3]

This lack of interest or willingness to engage with FND patients may stem from a lack of awareness of the disorder. Although FND is the second most common reason for neurology appointments (Stone et al., 2010), the lack of awareness and knowledge of FND was apparent in both healthcare worker and patient interviews. Patient and caregiver participants reported that they had never *"heard of it"* [CG3] until the patient received their FND diagnosis. Fascinatingly, some patient participants work (or previously worked) in healthcare services, and they reflected on how they were not aware of FND until their own diagnosis:

> *"Even though I've been in the ambulance service for 35 years, I'd never heard of it. And a lot of people haven't heard of it."* [PT5]

> *"I didn't really know much, which just shows how little there is, the number of you know…I was a physio myself and had never heard of it. I'm not a neuro physio, would never have been a neuro physio, but even so, I think it just shows how little understood it is."* [PT9]

Lastly, participants commented on how a healthcare worker's knowledge, expertise and confidence had an impact on the quality of care they were able to deliver to patients. Patients and caregivers reflected on the limited knowledge of healthcare workers in wider healthcare services, with some perceiving a lack of willingness to learn about the condition, "*now I know GPs can't know everything. But…do some research"* [CG3]. Others commented on how it felt like they were learning about FND at the same time as the healthcare workers who were providing care for them or for the person they support, reflecting that it was "*more like a mystery tour than the path of the recovery"* [CG1]:

> *"It felt like we were all reading textbooks at the same time. I don't think there was anyone around who had any experience, or it didn't feel like there as anyone around who was bringing anything to the table that I wasn't getting from Google."* [CG1]

This lack of knowledge and being on the same learning journey as the healthcare workers, may influence how a patient perceives health services. Patients may refuse to attend services in the future if they think that there is no added value in attending appointments due to a lack of well-informed information or care. Indeed, one patient commented that *"I just felt like if I went to the hospital, they wouldn't know what to do with me"* [PT1]. Interestingly, some patient participants relayed conversations they had had with healthcare workers, regarding the lack of FND knowledge in healthcare. These conversations may be exacerbating these feelings and further discouraging patients from having confidence in healthcare workers, or even accessing support in the future:

> *"I felt that they didn't have a clue what it was. Even after being diagnosed, my own GP – he was happy I had a diagnosis. I was in to see him one day and said 'at least I've got a name for my condition'. He said 'I wouldn't worry too much about that, they don't have a clue what's wrong with you, that's why they told you that."* [PT4]

Healthcare worker confidence and expertise were linked to many experiences and perspectives reported by participants. Curiously, one healthcare worker commented that it does not need to be a specialist who support these patients: *"it's not rocket science, it's just good people skills and, and listening and understanding people and their behaviour"* [HCW9]. This comment was supported by a patient participant who became emotional when visiting audiology, due to both their knowledge and supportive demeanour:

> *"They were aware that FND can have impacts on hearing, they were aware that it can be post viral, they were completely non-judgmental. I actually burst into tears a few times because they're the nicest people I've come across [laughs] and they tried to help me with it."* [PT8]

Fascinatingly, healthcare worker overconfidence (or arrogance) was referenced in several interviews and how it negatively impacted patient care. This arrogance led to one participant being unable to access suitable support as, "*the next [consultant]...he was a little bit too arrogant to accept his limitations and think, 'I don't know, I'm going to ask somebody'"* [PT9]. Healthcare worker participants also provided their own experiences of supporting patients in healthcare settings. Some acknowledged how few healthcare workers had received FND-specific training, and were inexperienced when working with FND patients:

> *"…very few people, even amongst qualified psychologists, I think would be able to confidently identify or work with or even vaguely understand what it's about. So no wonder the scale of the problem is so big because we have so few people able to respond when it does come up."* [HCW1]

5.3.3.1.2 Support from the community

Both patients and caregivers reflected on the range of community support they currently (or previously) receive. The comments from participants supported the survey findings which showed patients were not readily signposted to support from charitable organisations or other healthcare-based services, therefore participants explored other avenues for support. Interestingly, healthcare worker participants reflected on the reasons why they were reluctant to signpost, with one stating that *"signposting is not easy within our* [NHS] *Trust"* [HCW7] due to limited resources available. Perhaps due to a lack of confidence in outside services, another healthcare worker commented that they took a more *"passive"* stance, rather than *"specifically endorsing"* organisations and groups that provided support outside of their own service as they had no opportunity to *"quality control"* outside organisations [HCW3]. Due to healthcare workers being reluctant to signpost, patient and caregiver participants took it upon themselves to find relevant organisations and charities for support. Some expressed gratitude to these services, stating "y*ou know, we're lucky in the sense that we've got things like FND Hope UK which is fantastic"* [PT9].

Participants reflected on the importance of peer support, with one healthcare worker stating that "*peer support is probably one of the best treatments you could offer, probably"* [HCW1]. This could perhaps be because patients feel a sense of belonging, are able to support one another, or they feel that only those with the condition truly know what it is like to live with the disorder. Peer support was predominantly accessed online via social media platforms (such as Twitter, Facebook and Stuff That Works), with many participants providing positive experiences:

> *“I'm on a lot of the Facebook groups which are great, because they're really good. There's a kid’s one as well, which is good for everybody, and there's always people there that understand which really helps.”* [CG4]

> *“So my experience of social media is all through closed groups…we're closed groups and we support one another, and we talk to one another.”* [PT7]

Patients and caregivers described in detail the peer support they access online, with some using the social media platforms to discuss or compare their symptoms and experiences of accessing healthcare services. Indeed, some participants utilised this information to explore potential treatment avenues, *“we started following the Facebook groups just to see what, you know, what works and how we try and tap into that”* [CG7]:

> *“My wife found an FND support group on Facebook and so I've been…I’ve had a look on that to see how people are getting on and what their symptoms are compared to mine. And a lot seem to be having a lot worse symptoms than I am. They have fits - I'm not having fits. But I've got the fatigue and poor mobility, the left-sided weakness. So I’ve been putting comments about how I've been suffering with it."* [PT5]

In contrast, healthcare workers expressed great worry at the prospect of online support groups, with one stating she ‘bans’ patients from accessing online information or support groups as *“for some patients, that is not a clever place to be [due to] knowing their triggers”* [HCW6]. While the healthcare worker was trying to minimise the likelihood of symptoms being triggered, this attitude to limiting or ‘banning’ access to support may be perceived by patients as an attempt to exert control and could lead to a loss of trust, or even a breakdown in the patient-healthcare worker relationship. Other patients reflected on how they disliked online support groups and peer support due to personality differences:

> *“I mean, there’s support groups online and things, but people have got such varied symptoms. I always felt like, it weren't a place for me. Do you know what I mean? They weren't my people [laughs].*” [PT1]

> *“I've tried to, and being the person that I am - I will read other people's experiences. And sometimes that's not helpful for me, particularly if they're in a*

> *situation that I would consider to be worse than my own. So that's not helpful to me."* [PT10]

Although the majority of peer support was accessed via social media platforms, some patients attended in-person peer support, or in the case of some caregivers, were contacted directly by parents, whose own children were going through the FND diagnostic process. Caregivers reflected on the difficulty of the diagnostic journey, with one stating *"my heart just sank, and I just thought 'I wouldn't wish it on anyone'. I really wouldn't"* [CG1]. However, the caregivers in this situation still aimed to provide peer support to other caregivers starting this journey, due to a sense of camaraderie or a willingness to support others:

> *"I've had various friends of mine all over the country get their friends to phone me up because their kids are going through the same thing. They need someone to kind of unpack things, like what's going to happen down the line…It was good for her to hear me say, 'this is what I've learned. You know, school was a nightmare."* [CG1]

> *"I did actually video her [patient caregiver supports] having a seizure before we went into A&E…I was able to say, 'this is what they look like. So this isn't a one-off. This happened yesterday…So, because I just thought that, you know, that helps them, so that, I guess that's something I give the parents a tip to do."* [CG7]

Curiously, the patients who had access to in-person peer support were much less receptive to attending them than the patients accessing online peer support on social media platforms. Others felt that face-to-face peer support was not a *"beneficial thing to do [as] they were just all dealing with so much"* [PT1], their own outlook differed to others attending the group, or that it was a *"social event to just moan"* [PT2]. One patient participant with access to face-to-face peer support found it useful yet bittersweet, perhaps due to themselves and their peer already having a rapport established, as they were employed in the same workplace:

> *"…her and I would sometimes…she's only in her 20s. But her and I would sometimes sit in our break room, just holding each other's hand and just support each other. Because sometimes it'd be her sometimes, sometimes it would be me, sometimes the both of us, and we just go, we just go sit there, and just talk through that sort of stuff. And it was brilliant, but also really sad at the same time."* [PT8]

In contrast to these experiences, the participants who were unable to access peer support or other types of support (due to lack of availability in their geographic area) disclosed how it would be a good opportunity for them to meet other FND patients, in order *to "share experiences, and maybe help each other, and, you know, pass on some good experiences as well"* [CG5], because *"every now and then we all need peer support"* [CG6]. These feelings were supported by healthcare workers, who were unable to set up a formal peer support group in their service, due to a lack of investment in funding, time, and accountability of services and staff:

> *"Absolutely. Yeah. Because some of them you think, 'Oh, actually, I think you'd be really good for each other, in terms of education and stuff'. But actually, if we've got no formal way of doing that, then that's not appropriate! So it's just really difficult."* [HCW6]

> *"We would love to Danielle, but we don't right now. Partly because of…a lot of reasons, partly because of staffing required, partly because of the transition back from COVID and maybe some anxieties in the service about the flipping between remote and face to face, and also the question of whose role is to provide peer support. Because it's not active intervention from a clinician so to receive that should you be, should you be a patient, can we keep someone on our books who's getting peer support if you discharge them, then, how do you offer it to them?"* [HCW1]

Participants reflected on how their friends had supported them throughout their FND journey. Interestingly, one patient wrote an Instagram post in order to reciprocate support to her friends while undergoing diagnostic assessments in order to help them *"find the right balance between taking everything seriously, but also it not being the be all and end all, so just gently encouraging me to come out and do things and not staring or being frightened of the jerks or seizures, and that kind of thing"* [PT6]. One caregiver, who provides support to her teenage child, reflected on the difference between the support she received from her friends in comparison to the support received by her daughter's peers. These differences are perhaps due to age differences and maturity levels, with the adults being more capable to support their friend during such tumultuous circumstances:

> *"I enlightened some of them as to what was going on, they were good, really supportive…for me, like, you know, 'what can I do' kind of thing. With some of*

> *[name redacted]'s friends, it was more…they couldn't deal with it. That's not helpful. You know, obviously, her being in it."* [CG7]

Other patients reflected on how their friends supported them by providing advice or advocating for them. One caregiver explained how the friends they had made at their daughter's Girl Guides troop had arranged respite to support her "*if I need an hour off, or I want to go have a drink, go in a hot tub, that's fine. Just let them know and they'll watch her! [laughs] Honestly, they are the best group of women you could ever imagine!"* [CG4]. These sentiments were held by other participants, who had received support from their friendship groups:

> *"One of my friends has like, she has just been advocating for me. So she managed to even finesse her way into the hospital. And was saying that, you know… because when they were all trying to dismiss me she was like, 'she's not safe, she needs, she needs…she can't just be left to go home'. And just staying with me, making me meals, still keeping things light, not treating me completely different."* [PT6]

> *"There was a physiotherapist who worked on stroke [ward] who is a friend of mine. She found out about me obviously, she'd heard about what I had. And she was asking me if neuro physio [neuro physiotherapy] been in touch, I said 'no'. So she said, 'that's what the reason was calling you'. So she said, 'I'm not calling you, officially'. But she said 'you could try these things'. So she gave me some ideas on what to do based on her background as a stroke physio. So that was really useful, so she's given me friendly advice [laughs]."* [PT8]

5.3.3.1.3 Support from caregivers

Participants described (in great detail) their experiences of caregiver support, while accessing diagnostic and treatment services. Similar to the support received from friends, caregivers advocated for the person they support. Participants reflected on the importance of advocacy during the FND diagnostic journey: "*if you've not got someone who can advocate for you then you're totally screwed"* [CG3]. Caregivers advocated heavily in medical situations, with some *"badgering"* [CG8] and *"torturing [laughs]"* [PT4] services to ensure the person the person they support is assessed quickly by a healthcare worker/service:

> *"I was worried about the possibility of him losing his job, because he's telephone technical support, and his speech was declining rapidly. So I rang the GP, you know, because I kept ringing them to say 'how long?' 'it's like a five month waiting list'. I'm thinking this isn't good. So I rang up the GP and said, 'Look, you know, this is his job, and he's at risk of losing his job here'. And the GP did send a letter asking them to make it more urgent."* [CG3]

> *"She was in a cardiac ward in a private bay, it had to be a private bay because the other patients would have got up and left because she was so disruptive, and they just couldn't, just couldn't manage her. And then I kept saying she needs to see a psychologist, and then a neurologist, and all the rest of it. And she was in there for three weeks and I was badgering them every day."* [CG8]

Caregivers providing support for their child faced further challenges, as they needed to advocate at school as well as in the medical system. Caregivers of teenagers were especially worried due to their child not accessing services in a timely fashion, leading to further negative outcomes, "*She's just 16. If it's about neural pathways, are we not just letting time slip away from us by not doing anything?"* [CG7].

How involved a caregiver should be during the clinical management of FND was a focal point throughout the interviews. It is an interesting premise, as the caregiver may be able to provide key information needed to make a diagnosis yet including them not lead to patients not feeling comfortable to share their own perspectives. A balanced view of their involvement and support was provided by patients, caregivers and healthcare workers, with many agreeing that healthcare workers should be "*making sure that the person diagnosed is okay with caregivers being involved' as 'they're the patient, they're the one with it"*, then if they're happy with their involvement, making sure they are *"not being excluded from discussions"* [CG3]. This notion was further supported by the caregivers of children and adolescents, who felt it was imperative for them to be involved, but acknowledged that the child should also be involved *"if they're obviously old enough to be part of it"* [CG7]:

> *"I think you do need to involve the parents, because they're the one that's living it 24/7, you know, I had to sleep with her you know, just because if she had one and she wasn't breathing, I was on scene, I'd hear that, you know, that sort of thing... So yeah, there's things like that about involving, yeah, I would say yeah, that definitely affects the family. The whole family, yeah, as well as obviously the child themselves."* [CG7]

Some participants were more reluctant in the involvement of caregivers during the clinical management of FND, with healthcare workers succinctly explaining that *caregivers "can be hugely supportive if they can understand what's going on"* [HCW2], but that they can also negatively affect the care being offered:

> *"I've had mixed experiences of carers. Sometimes they are the biggest advocate for the stuff that I'm trying to do, sometimes all they want to do is care for their loved one, and they can be a hindrance as well as a help [laughs]."* [HCW6]
>
> *"People do usually tend to bring carers, and clinicians are varying about how much they encourage the carer to come in the appointment as opposed to just the patient. Sometimes it can be incredibly helpful because they see things the patient doesn't, including the symptoms. Sometimes it can be less helpful."* [HCW1]

This nuanced opinion was reflected by other healthcare workers who expressed that caregiver involvement (and subsequent support) "*is a difficult one because it is medical, it is private, all the rest of it. But I think they should be recognised as 'no, they don't have it, but they are part of it"* [CG3].

Lastly, a small number of comments focused on support for caregivers. As detailed in Section 4.3.5, caregivers felt an immense burden when providing support, and many wished to access support for themselves. Some caregiver interviewees expressed their gratitude for the support they received from charitable organisations (such as Carers Wales), stating they "*are brilliant"* [CG6]. Others accessed support from other caregivers, as they were able to "*offload in an environment which is non-critical, non-judgmental, where there's an understanding"* [CG3].

Some caregivers described in detail the type of support they would like to receive, mainly consisting of wanting to be *"able to speak to somebody…that probably might help"* [CG2]. Intriguingly, caregivers reflected on seeing the interview they participated in as support, as they were able to speak to someone who understood the condition and the caregiver role, while at the same time the interview data would be anonymised, so they were able to disclose how they truly felt:

> *"It would be good to be able to…in a sense, this is support because it's chatter. But at the same time, I know that this is very confidential."* [CG3]
>
> *"Actually, it's actually lovely to talk to you about these things, because I can say these glib things to you. I can't say it to her."* [CG6]

The caregivers using their interview as an opportunity to reflect on their innermost thoughts and feelings to an ‘outsider’ is an intriguing premise. It highlights potential data issues, such as participant bias where participants may not be willing to disclose their true feelings or experiences for fear of being judged by the interviewer. These potential issues were anticipated by the author, therefore before the commencement of each interview, participants were informed that their data would remain confidential and that they would remain anonymous. By reminding participants of these factors, it was deemed they would be more likely to reveal their true reflections, experiences and perspectives.

5.3.3.1.4 Support from family and loved ones

While participants focused on distal individuals and groups (reported in the text above), many experiences of support received from proximal individuals were disclosed by both patient and caregiver participants. Though (at times) family members did not really understand FND as a health condition or associated symptoms, participants appreciated the support they received from them. Patients reflected on how family members found it “*really hard”* [PT4], or that they “*probably had it hardest, you know [as they had to] get their heads around it”* [PT1], yet were still *“extremely supportive”* [PT9]:

> *“They're quite supportive. In terms of that…they don't really understand it. So they understand that sometimes my mobility is impacted by it. They understand that sometimes I have fatigue, and I'm just tired, and they just do their best to support really, but in terms of fully understanding what it is, it's, it's hard for people to understand.”* [PT10]

Patients were prompted to detail the types of support their family provides. A wide range of answers were reported, including medical support, childcare and emotional support. Curiously, a small number of participants had family members who were physiotherapists and were able to provide advice on potential treatments and other professionals to contact:

> *“My sister, who is a physio down South, she found me the physio. And then the physio found me the psychologist.”* [CG1]

> *“I have a cousin who's an MSK [musculoskeletal] physio, she works in Canada, she gave me some more advice.”* [PT8]

While having access to a family member with medical knowledge and expertise was seen as a benefit to most, one caregiver reported that it was not always useful to have medics in the family, perhaps due to receiving conflicting or unsolicited advice:

> *"Um, I think, I've got a lot of medics in my family which helps, and sometimes doesn't [laughs]."* [CG1]

Continuing with this focus on medical support, family members played a large part in encouraging patient participants to access health services (when they did not realise the severity of their symptoms):

> *"...he [partner] had physio for his hands for a period and then was discharged, and then he still wasn't getting any better. And then he was having trouble getting up from a sitting position, he couldn't do it, sort of thing. And again, '[partner] you need to see the doctor."* [CG3]

Family members were able to provide different kinds of support. Adult family members (such as the patient's parent) were able to provide support by researching techniques to improve their symptoms and were also actively involved in their recovery:

> *"I mean, when at the beginning, you find all sorts online and we saw this research that said 'if you can't walk forward, walk backwards. If you can't walk, you'll be able to run', so me and my Mum spent ages on…her street and the neighbours must think we were lunatics because she got me out of a wheelchair and be like '<u>go, run</u>!' [laughs]. Sometimes I fell, but sometimes I could run! And I could walk backwards, and then we did loads like practising with my legs and we did all sorts of stuff, getting me up and going. And once I knew I could do it, it kind of stuck."* [PT1]

Conversely, participants with children placed an emphasis on how their children supported them (or in the case of caregiver participants, the person they support). One patient participant with a young child who could not remember them before they received their FND diagnosis reflected on how it's 'second nature' for their child. For example, when they suffer from tremors, their child used distraction techniques or provided emotional support to help alleviate their symptoms:

> *"…Thankfully I didn't have a violent tremor but the normal shaking as I call it, the daily shaking, the right arm was going. I was sitting with my wee girl and she said 'Daddy are you alright?'. She asked me a couple of maths questions – it's just second nature, not a care in the world which is good, you know."* [PT4]

This perspective was supported by a caregiver participant, who feared letting wider family members care for her child who had an FND diagnosis, as they did not understand how to handle the FND symptoms, whereas her older daughter *"can deal with it"* [CG4]. Another caregiver reported how a lack of understanding of FND caused family members to be scared to look after her daughter when she was a child:

> *"None of my immediate family would look after her, they were terrified. She just scared them."* [CG6]

A small number of comments described how family members were unable or unwilling to support. Participants with adult children noted how their children *"really struggled"* [PT3] seeing them not as mobile as they were previously, and that it was *"hard for them to watch"* [PT3]. This perhaps highlights the resilience of smaller children, who were much more accepting of FND, and the limitations of their parent. Another caregiver noted how their family members avoided speaking to the person they care for:

> *"...our son doesn't seem any different with him, but he probably doesn't ring him like he used to. I would say my father, he's in his 80s - I sometimes find my dad speaks to me, rather than [spouse]."* [CG2]

Interestingly, a healthcare worker reflected on how they noticed the contrast in family support with their patients, perhaps due to financial and socioeconomic stressors in place:

> *"I mean, a lot of the relatives I've come across have been really, really supportive. So the chap with uber amounts of stress, his wife was so on board with everything and so supportive, and…but they're quite intelligent, both of them. And then my poor lady with the really, really low socioeconomic background. The only thing her husband was interested in was keeping a roof over their head. He didn't want to know about FND, he didn't want to know what was wrong with her. He didn't know… he didn't want to know how best to support her. He was just working all the time to keep a roof over their head."* [HCW2]

5.3.3.1.5 Support from school and work

Lastly, the experiences of vocational and school support were discussed. Experiences relating to school support were predominantly negative; caregiver participants perceived their child's school as being unable and unwilling to support them returning to school and being safe there. Participants reflected that schools just "*didn't get it"* [CG7] and were dismissive, having an attitude of "*pull yourself together"* [CG7] rather than being supportive.

One participant perceived that although school was *"incredibly frustrating"* [CG7], they were not aware of how they could support their child, as she was the first child in that school with an FND diagnosis. This lack of awareness and understanding was expressed by another caregiver, as their child's school *"freak[ed] out over her condition"* [CG4]. Indeed, both caregivers expressed the difficulty in getting their child to school and how each respective school did not support their child's return:

> *"One of the days she [the person the caregiver supports] managed to push herself. She got up paralysed, got dressed in a school uniform which is, you know, the full suit job now like they do, the blazers, the trousers and everything. Fully paralysed, got everything already, ready to go. Got over that barrier of people seeing her paralysed, got to school. 'Oh, no, she can't come in'. 'What?' 'We haven't done the risk assessment for the wheelchair'. I'm like 'it's been here for six months. You know she needs it. You tell us it's here to use it. And now when she turns up, you're turning her away?'. So that was like a slap in the face that, you've managed to get yourself here over all your hurdles. But 'no, you're not coming in'."* [CG4]

> *"…what I found incredibly frustrating…the way that just the timetable would work. There was a day that was quite a full day for her, so she'd come home for lunch and quite often, I'd go, 'come on let's go', and she'd be absolutely passed out. 'I can't move'. So I said to school, 'can we do lessons at home online?' The texts are there from lockdown?' The teachers were on board with it, but then they said, unfortunately, [the education department] say you can only home-school if you've got COVID. I went absolutely nuts. And I contacted the [education department].to basically just say, 'this is ridiculous. How many other children are excluded, whether it's because they're having cancer treatment or whatever, they want to learn why are you stopping them?' It's not like you know, someone's a bit tired and they want to do their R.E. from their bed. This is different. [laughs]."* [CG7]

These experiences differed wildly from patient and caregiver participants who experienced positive support from their workplace. Patients reflected on the support they received from their occupational health departments, with one even commenting that it was their occupational health professional who believed that their symptoms were because of FND:

> *"…if it hadn't been for that occupational health doctor, on his last consultation with him mentioning this as FND, I don't think I would have been diagnosed with it."* [PT5]

While another patient commented that their occupational health was not *"too bad"*, they did perceive that they were not well supported, as they were put *"on stage two disciplinary [laughs]"* [PT8] because their sickness absence was due to FND and not COVID. Others reported on the support they had received from their manager and how their work could be adapted to support them:

> *"I think it was my manager who suggested an occupational health assessment yesterday, because I said, 'actually, it's getting to the point where I feel like I can't walk. Yeah. And I'm feeling unsteady on my feet'. And I couldn't even get to the printer from my desk yesterday. And this is a very new experience for me. It was her who said, 'Okay, we need to speak to occupational health to see how we can support you to, you know, adaptations."* [PT10]

> *"My senior charge nurse called me in because she was concerned about my health and that, and so it was semi-formal. She just wanted to touch base and talk me through things. So she was suggesting that I might need to get in touch with our wellbeing hub for staff.'* [PT8]

Caregivers also reflected on vocational support, both in terms of their own support and the support for the person they provide care for. Caregivers commented on how their manager *"was brilliant"* [CG6], were *"lucky that [their] employer let [them] have time off"* [CG7] and were grateful that their spouse's employer *"opened some doors to private treatment"* [CG1]. Unfortunately, not all workplaces were supportive. Two caregivers reported how their (or their spouse's) workplaces were unwilling to allow them time off to care for their children when they were newly diagnosed with FND:

> *"...they were getting really nasty about it, 'we need a date when you are coming back'. 'I need a date for when my daughter can go back to school, when she's not il".'* [CG4]

> *"…his boss was saying, 'oh, you can't keep going away'. You know, they weren't very supportive, even though his daughter was in the mental health unit."* [CG6]

From the experiences and perspectives provided by patients, caregivers and healthcare worker participants, the role of the ‘village’ in supporting an FND patient is imperative to their wellbeing. Patients and caregivers described their experiences of dismissive behaviours and attitudes from healthcare workers when accessing diagnostic and treatment services, leading to patients and caregivers seeking support from other avenues, primarily peer support. Peer support was predominantly seen as a positive experience as it gave patients the opportunity to talk to others who understood their symptoms and perspectives. Lastly, support from family and loved ones, as well as vocational support, allowed patients and caregivers to focus on recovery.

5.3.3.2 Theme 2: The art of communication

Theme two highlights how communication between healthcare workers, services and patients is imperative during the clinical management of FND. Participants reflected on language use, information sharing and searching, as well as the patient-healthcare worker relationship.

5.3.3.2.1 The patient-healthcare worker relationship

The patient-healthcare worker relationship refers to how the patient and healthcare worker work together, leading to a development of a consensual, professional relationship (Ridd et al., 2009). As stated by Chipidza and colleagues (2015) loyalty, regard, mutual knowledge, and trust must be incorporated in order for the patient-healthcare worker relationship to exist. These factors are influenced by communication. Many patients reported a lack of communication when interacting with healthcare workers, with one becoming upset as the healthcare worker chose to speak to his wife over him:

> *“Sometimes they weren’t even talking to me. They were talking to [name redacted] and I was thinking “speak to me and I’ll try and tell you”. It was like I was an idiot and she’s my carer. She’s not my carer, she’s my wife.”* [PT2]

This limited communication between healthcare workers and patients may be due to a lack of ability to adapt to different situations, whether due to the healthcare worker’s lack of experience or the inflexibility of the service. For example, the patient in the quote above struggled with aphasia, yet had the ability to communicate by using a pen and notepad. Some patients found the development of the patient-healthcare worker relationship was stifled due to *“no follow up, no continuity, no contact”* [PT9] from healthcare workers, leading them worried that they had no one to contact if their symptoms became exacerbated:

> *"The neurologist thought it was FND, when I was in the hospital, he said he was going to check on something, but I didn't see him again. He didn't come back."* [PT2]

The utilisation of turn-taking during conversations was highlighted by both patients and healthcare workers. Healthcare workers perceived their conversations with patients were reciprocal and encouraged patients to share their thoughts, while simultaneously acknowledging the experiences a patient may have had before attending their service may impact on their reluctance to engage:

> *"Sometimes [patients] come thinking that they've just been dumped on you because they've seen everybody else, so what difference are you going to make? And that's where I think it's so important to be positive and optimistic for them. "You tell me why you think you're here. I'll tell you what I think I can offer you. Let's just have a little chat about what all this is from your perspective", and from the carers too."* [HCW6]

Contrasting this, patients perceived that healthcare workers ignored their concerns when communicating during their appointments, leading them to believe that the healthcare workers had already made up their mind, and did not want to discuss other possibilities:

> *"…if the seizures had only started after the traumatic incident, then maybe, but because I had the seizure on New Year's Eve, I was with friends, I just had an amazing holiday in Iceland. I was really happy. And then she said, 'oh, it's because you're not used to that in your life', or something. Because I've had past trauma and so it was like, yeah. But it just feels like…it's almost like, 'we've got a reason and we're going to try and wedge in to fit our picture'."* [PT6]

> *"He [the healthcare worker] just decided. And the second time that I saw him…when I saw him a year later, when I was significantly better but not, not where I am today. He kind of decided that something else in the family must have happened [laughs]. So he was quite…clutching at straws. I felt a bit like he'd got a narrative that he decided what FND was, and he fit me in that box no matter what, what it would take."* [PT1]

Shared decision-making is a prominent part of the development of the patient-healthcare worker relationship, as both the healthcare worker and patient need to collaborate in deciding the next steps of healthcare and support. Healthcare worker and patient participants' perceptions on shared decision-making differed vastly, with patients reporting they were not involved, or that *"[the healthcare worker] kind of just said, 'these are the treatments that you should get'"* [PT1]. However, healthcare workers expressed that *"of course patients are involved, they should always be involved*" [HCW9]. Healthcare workers were passionate about involving patients and caregivers in treatment options and treatment goal decisions, with some allowing the patient to lead the decision process in a safe way:

> *"...you know, you ask the patient, 'what would you like to get out of this?' and they say, 'I want to be normal', understandably, so that does have to be unpicked, of course, and then coming up with, you know, goals that that they want things that they would like to achieve is so important. It really does have to be patient-led. And sometimes that might have to be a compromise. But yeah, so I would, I would say yes, patients should be heavily involved in the kind of activities they're involved in."* [HCW7]

Healthcare workers reflected on collaboration and shared decision-making between themselves and patients, finding that it *"works better because it's recognising that it's starting with what the patient thinks is the most pressing thing for them, and what they feel comfortable working on"* [HCW3]. These thoughts were mirrored by patients who were not involved in deciding appropriate treatments, admitting that they were confused by being referred for treatments such as psychotherapy, when they felt they did not need it, as the onset of their FND symptoms was caused by a spinal surgery.

All three population groups reflected on how information was communicated in appointments, with some focusing on providing clear explanations. Healthcare workers provided accounts on how they relay information clearly to patients, noting that when patients have accessed their service previously it may *"be one of the first times people have felt they've been given an explanation for their symptoms"* [HCW3]. This perspective was mirrored by some patients who felt that their diagnosis was explained in *"quite a simple way"* [PT5].

The ability to explain information clearly and turn take were just two communication skills which featured throughout the interviews. Strong people skills are not only vital to support

FND patients, but are also fundamental in the development of the patient-healthcare worker relationship. Indeed, people skills helped healthcare worker participants build a rapport so that their patients trust them, causing the patient-healthcare worker relationship to develop:

> *"I really try to see [patients] really regularly when I first pick people up, just so that we can get this rapport building going. And I tell them that's what it's for. Because for some of them, it's too scary to do anything else. And I'll say, 'right, but what we know from the research is, if you trust me, then we might see some progress. So I'm going to see you next week. And we'll just chat a bit more about how things are with you, let me get to know you, let you get to know me a little bit. And let's see where we can go'."* [HCW6]

Healthcare workers discussed how they used candour and validation to build rapport with patients, stating they are always honest because they *"want to help [patients] and that's the most important thing"* [HCW6]. This honesty was appreciated by patients and caregivers, and helped build loyalty and trust:

> *"Dr [name redacted] managed everything, she said, 'this is very expensive, all these…all these tests that we're doing'. But she said, 'I don't care. It's important that we rule-out everything before I give you my diagnosis'. And I really did think that she was brilliant. She was brilliant. I wish she was still in his life now and then maybe things will be better. But she was really, really good, she was."* [CG5]

Feelings of validation were mixed amongst patients and healthcare workers, with healthcare workers stating they give *"a bit of validation of their symptoms"* [HCW10]. Indeed, one healthcare worker who supports patients in a rehabilitation team reflected on validating a patient's FND diagnosis when she *"felt like a fraud"* [HCW5] due to her symptoms improving after a few days of attending the rehabilitation service:

> *"I had someone recently who'd had symptoms for like at least 20 years. And she got better by the Friday. And her reaction was, 'I feel like a fraud'. So she was really, really low…And I was like, 'Yeah, but you had a week of like people who know about FND telling you about it all week, and showing you like how to do things and giving you tips and tricks, and you're not at home'. Because they stay in a hotel room on site, we have a hotel as part of the hospital. So sometimes just removing them from a stressful home environment can just help!'* [HCW5]

These sentiments were not shared by patients, whose feelings were invalidated when interacting with healthcare workers:

> *"The [doctor] who asked me about the drinking, 'take a drink, take a drink for that and we'll be able to distract your tremors, it's nothing serious'. But you're not the one that's been banging about the floor. He didn't have a clue, he was a neurologist and he spoke to the head neurologist on, and he said 'no, we don't need to keep him, we'll just see him in outpatients, we'll get him an appointment. Away you go, we need the bed'."* [PT4]

Feelings of invalidation may have been substantiated by healthcare workers who may not have been fully aware of the disorder, or perhaps by a lack of empathy. Patients reflected on the empathy shown by healthcare workers, and how it allowed themselves and their family to understand and accept the condition:

> *"[Text read from a letter] 'My wife, my son, my daughter, and I have been overwhelmed by the compassion, care and courtesy of all the staff. Particularly the neurologist, Dr. [name redacted] for her rapid and professional diagnosis. And to [name redacted], who patiently explained it to us when we were bewildered and confused about the condition. But all of the other staff too were fantastic'."* [CG6]

Showing empathy and compassion led to patients feeling that they had *"been heard"* [CG3] and could trust and be vulnerable around the healthcare workers who visited them at home. Interestingly, healthcare workers reported using their listening skills in order to allow patients to feel comfortable when confiding in them:

> *"But I do have a background in listening therapies and such like, so I feel that I use those skills without being…without crossing boundaries. But I feel that it gives me skills to be able to let people talk to me and tell me things."* [HCW6]

5.3.3.2.2 Information sharing

Throughout all stages of the clinical management of FND, communication and information sharing between patients, caregivers and healthcare workers is imperative to ensure an accurate diagnosis and suitable treatment plan. The experiences of information sharing were expressed widely by patients and caregivers, who perceived that information from healthcare workers and services was either not shared clearly with them or not at all, leading to confusion, bewilderment and worry. Experiences of misinformation and misdiagnoses were also discussed by caregiver and patient participants.

Healthcare worker and patient perspectives differed greatly on the communication between the two population groups, and how information relating to the condition was relayed. Although healthcare workers were aware that communicating the FND diagnosis is a *“difficult conversation”* [HCW7], patients were left feeling confused or upset due to the abrupt language used:

> *“...there was a bit of an attitude of ‘he’s alright’ kind of thing. That’s exactly what the consultant said, ‘You’re in a wheelchair, get on with your life’.” [*CG1]

> *“[I] came across a young lady who’d had horrific domestic violence as kind of her background in developing FND, and a neurologist saw her in [hospital redacted]…the neurologist told her that she was an unfit mother and that she couldn’t look after her children.”* [HCW2]

“Medical jargon” [PT7] increased feelings of confusion; yet there was an understanding that it may be difficult for healthcare workers to code-switch when communicating with healthcare workers and patients:

> *“…it’s almost like such familiar bread and butter to the consultant. It’s the lack of understanding, that’s it’s the foreign language to the patient. It’s like if I try and explain my work to somebody, I’d be using acronyms and abbreviations and what, which I’m totally familiar with and understand, forgetting that actually I could talk in Russian to them.”* [CG3]

Healthcare workers discussed their own communication styles and how they shared information with patients, while reflecting that they feel *“responsible for [their] profession because these patients don’t always get a good deal”* [HCW10] and aimed to validate their patients’ feelings and symptoms:

> *“I often meet people who’ve been diagnosed once, maybe six months ago or years ago. And they might not be fully aware of what FND actually is…, a lot of my time is spent on education and really just trying to capture all of their symptoms. And then the ones that I’m able to address and show them that they’re functional, like I*

> *said, and communicate how, what the mechanism, what other factors might be driving these symptoms, if we're able to identify any."* [HCW5]

> *"Most of the diagnosis for me is based on examination findings, but then what I will do in virtually all of my FND patients, is an MRI. And that's as much for them as it is for me, to show - them to reassure them, 'Look, I've looked at your brain in great detail. And this is, this is supporting my diagnosis of FND'."* [HCW10]

This responsibility was reflected in patient and caregiver experiences, explaining that healthcare workers need to be able *"to communicate the diagnosis to patients in a way that they understand…otherwise it's confusing"* [PT2] while being supportive:

> *"…it's FND by process of elimination, almost. Instead of 'alright, okay. So the good news is, it's not this, it's not that, the bad news is, obviously there is something wrong. And we can understand that. And it's very real, and your symptoms very real, we know you're not making it up, there's just no structural abnormality that we can pinpoint it on. But it's where the system is going wrong. So there are ways that we can deal with this to improve it and to manage it, and it doesn't necessarily mean it might get worse, your chances are it will get better with good management and self-management and change of your lifestyle'. You know. And I think just something like that would have been so helpful and so supportive, and I wouldn't have felt so…at the back of my mind, 'have I caused this myself, am I making it up?'"* [PT9]

A minority of patients received detailed and compassionate information regarding their diagnosis, with healthcare workers taking the time to talk through the condition, and why certain diagnostic tests were used to determine the diagnosis:

> *"Radiography were brilliant as well. They were saying, 'well, if it is FND we almost certainly won't see any sign of it'. But they talked me through what they'd seen in previous patients with FND and how it can manifest in different ways, but they could see it in me that matches some of the FND patients they've had before. And they were the ones that told me about how some people have dropped attacks, some have non-epileptic seizures."* [PT8]

These experiences and perspectives were not shared by other patients and caregivers, who resorted to accessing private healthcare to receive more information about their condition: *“they explained a lot of things better. Well, it couldn’t have been much worse than the first one, to be honest”* [PT2]. Patients experienced short and at times, curt, conversations with healthcare workers; patients were unable to ask follow-up questions to calm their concerns:

> *“I think once they’ve done the bloods and said, ‘it’s not epilepsy’. It was like, ‘well, see you later’. I literally said to the doctor, ‘and how am I supposed to get her out the door?’.”* [CG7]

> *“They worked it out pretty quickly because I was in the right hospital on the right day, and that sort of thing. So then the consultants all left, about 20 minutes later, a registrar came through and said ‘there’s no clinical pathway for this, so we’re discharging you’.”* [PT8]

Analogies were used to explain how FND affects the body: *“the hardware is fine, the software’s not. Think of it as a computer”* [CG3]. Analogies were used with mixed success, perhaps because of the confidence of the healthcare worker and the information given to the patient. The healthcare workers who deemed themselves as FND experts felt confident in adapting their language and analogies used to convey information, in order to encourage patients and validate their symptoms:

> *“I only became confident of particularly around what language I use with these patients. That comes from experience, it really does. And that’s the difficulty is that it feels really awkward at the beginning but once you’ve seen numerous patients with this condition…I think the sort of language you use and what sort of analogies you use, based on that person in front of you and their level of understanding.”* [HCW2]

> *“I’ll sometimes use the analogy of walking backwards. And how, if you walk backwards, you have to think about walking, and therefore walking backwards is an odd thing to feel. You don’t feel steady, you don’t feel right doing it. Or I’ll sometimes use the example of…I always say like Serena Williams doesn’t think about every stroke she makes with her tennis racket, if she did, she wouldn’t be able to play tennis as well as she does, because she’s not meant to think about it now.”* [HCW10]

However, the use of analogies (when explaining the FND diagnosis) concerned participants: *“it doesn’t really help explain what they’re actually talking about!”* [HCW4]. This concern was warranted, as one patient did not have the condition fully explained in her diagnostic appointment and was further confused when her discharge letter stated she has medically unexplained symptoms, not FND. These feelings of confusion were expressed by patients and caregivers, when receiving information on treatment options. A lack of engagement from healthcare workers (when communicating potential treatments was perceived, *“there was just nothing. You know, it was just the diagnosis”* [CG2]. This was a common experience reported throughout the interviews:

> *“No, ‘what we’re going to do is take you off the tablets, this is what you need to do’. I was just told, ‘basically, this is what you need to do, more or less. No magic wand. You just need to distract yourself whenever you’re shaking’. But obviously you’re going crazy, how are you supposed to do that?”* [PT4]

These feelings of confusion and lack of engagement were mirrored by another patient, who was also not signposted to relevant materials and information, *“they didn’t even give us [information]…I don’t even think he gave us a website to look at”* [CG3]. Indeed, patients and caregivers wished to be signposted to relevant information and organisations in order to further support them and *“gain knowledge”* [CG8]:

> *“…we just need someone to say ‘this is what it is, and this is what we need to do to help you get through this’ and to support you get through this…and just to signpost where to go because there are, there are so many services, so many third sector services out there.”* [CG6]

Although patients were not signposted to relevant information and organisations, others were signposted to *“that website [www.neurosymptoms.org] [as] ‘there’s a bit of information on that’”* [PT4], *given “some leaflets”* [PT8] or given *“two print-offs [and told to] get on with it yourself”* [CG4]. These experiences were not shared by healthcare workers, who discussed how they passively signpost patients to resources, ensuring their patients receive relevant and accurate information. Signposting to official sources was a point of concern to healthcare workers, who worried about the *“quality control”* [HCW3] of organisations. Interestingly, these feelings were not mirrored by the healthcare workers who provided the FND diagnosis to patients, who told the patients to *“go home and Google it”* [PT1]:

> *"I tend to signpost to Jon Stone's resources as something that they can go and look at themselves. Also, I tell them not to Google it, because if you Google it, you'll end up with a whole heap of nonsense on the internet."* [HCW10]

> *"I don't specifically signpost them to any specific other organisations…I guess one of my anxieties is sometimes I have no idea about the kind of quality control, if that makes sense. So rather than specifically endorsing things, I will say 'these things are available, if you wish to participate in them or to have a look at them', and that side of things."* [HCW3]

Due to the perception of not receiving a sufficient amount of information about their diagnosis, treatment options or even FND itself as a condition, patients and caregivers independently searched for information, sometimes to the dismay of healthcare workers who were worried they would stumble across inaccurate, misleading or even harmful information. Patients turned to *"Dr Google"* [PT4] or social media as they were unsure of their diagnosis. The usefulness and wariness of accessing information on Google or social media displayed by healthcare workers was also noted by patients, hoping that *"what [they] found out was right"* [CG5]:

> *"Twitter is where you can learn so much, or you get information that's interesting and the other is where people are just going to…they've got issues and gossip."* [PT9]

Those who had access to academic journals and conferences utilised them to find out *"more and more information"* [CG5], leading them to commiserate that FND research seems to *"come to a dead end"* [PT9] and there has not been wider discoveries to support FND patients. These feelings were supported by healthcare workers, who admitted to also accessing FND literature and information via podcasts and the 'professional' side of Twitter:

> *"…there are two [websites] that I get information from and also maybe sometimes get links to podcasts and things like that. I'm often, you know, this is where I think Twitter is a bit of a double-edged sword, you know, but I do find that professionally, Twitter can be incredibly useful. So that's where I get my information from."* [HCW7]

Although patients and caregivers alike used the internet to source their information, patients wished to source their information from a dedicated FND specialist. By having access to a dedicated specialist, they could alleviate their worries or receive advice instead of having to navigate websites. This suggestion was supported by a caregiver who approached a supermarket pharmacist for advice on potential medications to alleviate pain:

> *"[There should] be a nurse or some kind of support, where you could just ring for advice or just speak to someone even, you know, even if you don't use it, if they're there as someone to fall back on, rather than us just Googling stuff night and day."* [PT1]

5.3.3.2.3 Communication between healthcare workers and services

Communication between healthcare workers (whether in their own service, or when working in a different team or NHS Trust) is essential to ensure patients receive accurate and timely care. Patients may access a range of services across NHS Trusts during their diagnostic and treatment journey, depending on how they present with symptoms (for example, reporting symptoms to their GP, who then places a referral with a neurology services, or being admitted to accident and emergency due to having a seizure, and then being admitted on to an inpatient ward), leading to healthcare workers across services needing to pass on information to one another. Healthcare workers shared information on how they communicate with other professionals, when asking for guidance or advice on complex cases, whereas patients and caregivers' shared experiences on how communication between healthcare workers was limited.

Effective communication between healthcare workers (employed in different services) led to patients being given medical appointments in a suitable time frame, as it allowed for healthcare workers to *"expedite appointments quickly"* [HCW8]. Healthcare workers, who communicated between services, were *"brilliant…couldn't [be] faulted"* [PT4]. This outcome was further increased by healthcare workers who also communicated effectively with patients, with one patient being referred to a neurology clinic after making an off-the-cuff comment to their GP:

> *"So I saw [the GP] in April, and he asked how things were and I said, 'if anything, getting worse'. And I said that as a result, I've finished work because of this. I said occupational health mentioned FND. And he went 'ah!' and he got his mobile*

> *phone out and found a consultant in [place redacted] hospital. I saw him last Friday, and he's confirmed as FND."* [PT5]

Communication, both within and between services, instigated relationships to develop, leading to healthcare workers being able to collaborate and agree to *"reciprocal arrangements"* [HCW10] between services, when providing care and support to FND patients:

> *"So if they need in-patient, very intensive support to get over their FND relapse, we have an agreement that we will admit them to stroke services, because from a nursing and therapy point of view, we can manage them very, very well whereas other areas of the hospital maybe can't. So the payback to the FND service is that if they have an FND patient needing inpatient care…so we've for example, we have a patient who part of her FND trigger is around family tensions. Which means that if she relapses, she can't stay at home because the family tensions get worse. And then that makes her FND worse. So we will tend to bring her into the hospital as an inpatient if she needs it. And I will take her on to the stroke unit, even though she's not a stroke patient, because we can look after her very well and support that FND therapy. And so we got that nice reciprocal relationship going on."* [HCW10]

The locality of the services and healthcare workers played an important role, both when communicating and building relationships between teams, with those in rural settings finding other healthcare workers *"really, really welcoming"* [HCW8]:

> *"…in many parts of the country, the services don't exist. And, and yeah, if you have a telephone triage and you say you're not too depressed, and they say you don't, you don't need treatment. I mean, so. So, yes, so this very much kind of building relationships. And locally, that's much easier with local psychiatry or physios or GPs."* [HCW9]

Relationship building allowed healthcare workers to have more opportunities to ask for advice and guidance from their peers. Indeed, healthcare workers employed in multidisciplinary teams found that they were more able to communicate with one another and could readily support their patients:

> *"…we tend to do a tag team effort in that sometimes I'll go and come out thinking, 'hmm, I think this is FND'. And then one of my physio colleagues will go in, and I'll say, 'Look, I'm thinking of FND. Tell me what you think'. They'll come out and go, 'Yeah, I think this is FND, too'. So then I'll go back in later on, and deal with the explanation of FND. And then the physio will go in and go, 'Right. I know the consultant explained to you about FND, I'm now going to work with you and show you how we're gonna get round it'. That sort of teamwork works quite well."* [HCW10]

Interestingly, communication and information sharing between healthcare workers led to some becoming reluctant to refer patients, in order to ensure they would be supported appropriately:

> *"Well, initially, the idea…somebody had advice that I should send them back to the GP, which is fair enough for them to link in with different services. However, the neurologist had said the GPs have no understanding, have no experience, and there'll be forgotten about. So that's why I was reluctant to send this individual back to the GP for support, because I knew once I let them go, they're going to be lost. They're going to be forgotten about."* [HCW8]

Although many experiences were generally positive in nature and led to collaborative work with patients being referred to services and not being forgotten about, patients found that at times their care was impeded, due to a lack of communication between healthcare workers. Indeed, one patient became distressed because different healthcare workers *"repeatedly asked him about what happened to the lead up to him being poorly"* [CG5] but did not update their notes to inform other healthcare workers on the onset of their FND symptoms. Worryingly, another patient had an accident during a hospital stay, and found that healthcare workers did not record the incident:

> *"I fell off the chair in the hospital. One of the nurses came in to ask if I was alright, I said "it happens all the time", 'did you bang your head?', 'no', 'you're alright'. There was nothing wrote [sic] down anywhere, I just laughed to myself. I said to the neurologist, 'she came to speak to me, I had a wee fall, did anyone record it anywhere?', 'No'."* [PT4]

The findings of this theme highlight the intricacies of effective communication during the clinical management of FND, and its impact on the patient-healthcare worker relationship.

Language use and analogies tended to hinder the diagnostic conversation, with patients and caregivers alike leaving appointments bewildered and upset, due to not understanding their FND diagnosis. Effective communication between healthcare workers (for example, participant HCW8 receiving clear guidance from a consultant doctor working in a different service regarding whether a patient should be referred directly to a specialist clinic or return to receiving care from their GP) led to better quality of care and more timely care for patients, as well as developing reciprocal relationships between services.

5.3.3.3 Theme 3: Resources: the barrier to effective and timely care

Theme three details the impact of NHS resources on the clinical management of FND. Participants reflected on the barriers to accessing services, utilising private healthcare (due to lengthy waiting times) and implementing multidisciplinary teams (MDTs).

5.3.3.3.1 Waiting times

Due to severe budget cuts to NHS services (Vize, 2022), it is not surprising that patients and caregivers in this study reported having a lengthy wait to access diagnostic and treatment services. At the time of writing, approximately 7.2 million people were on a waiting list to access NHS treatment services, having to wait 14.6 weeks (median time) before accessing treatment appointments. This figure has dramatically increased since the COVID-19 pandemic; pre-pandemic, the median waiting time to access treatment services was 8.4 weeks (British Medical Association, 2023). A wide range of experiences on waiting times were provided by all population groups, from those who accessed services *"within a couple of weeks"* [CG5] to waiting over two years and still not having *"had the CBT"* [PT9].

Those who accessed services quickly were *"pleasantly surprised"* [PT10]. The majority who had shorter waiting times were accessing child services, which is expected, as the median waiting time for children's services was 11.8 weeks at the time of writing (Royal College of Paediatrics and Child Health, 2022). Caregivers reported that their child's appointment was even *"rushed through because of the FND [and] gobsmacked how quick she got to see them"* [CG4]:

> *"I think we were seen by CAMHS fairly quickly. I think he did see CAMHS before the summer holidays, so about six weeks or so which isn't bad for CAMHS."* [CG1]

Healthcare workers discussed the waiting times for their own services, ranging from *"14 weeks* [HCW8], between *"three and nine months depending on time of year"* [HCW5] and *"at least a year"* [HCW7]. These waiting times were reflected in the experiences provided by most patient and caregiver participants, who were waiting at least six months to access services:

> *“Well, I’ll be honest, when the GP initially…the student doctor initially said, ‘we’re going to speak to a neurologist’ that was in October of 2021. So from October until the 20th June, it’s actually a longer wait just to see the neurologist.”* [PT10]

Although *“a long waiting list is expected”* [PT9], waiting lists for some services were well above the reported median waiting time, with some being over two or even three years. Participants speculated on how services managed these extreme waiting times, with some believing that services were *“closed to new referrals because [they have] a two year waiting list”* [PT9], whereas others believed that services implemented strict eligibility criteria, which patients may struggle to meet:

> *“There used to be a concept, a misconception, I believe, that you need to be like on board with the diagnosis in order to get better or to be eligible for rehabilitation. So some services do operate that way, because they have to, in order to, because their waitlists are like three years long, and they will just keep adding to their exclusion criteria in order to try and manage that. So they’ll say, “Okay, if somebody’s really doubting the diagnosis, let’s take the person who has no doubt over them.”* [HCW5]

This eligibility criteria may have influenced patient behaviour, or even excluded patients from services due to not immediately accepting their FND diagnosis. This is problematic, as it has been reported that patients may not accept their FND diagnosis due to their experiences of accessing services (Fouche et al., 2019, Rawlings et al., 2017). Therefore, this causes a self-fulfilling prophecy situation, where patients may further reject their diagnosis, due to having additional negative experiences with healthcare workers and services because of their removal from the service’s waiting list. As well as patients being removed from waiting lists (due to no longer meeting eligibility criteria), participants reported situations where patients were *“forgotten about”* [HCW8], or “*fell off the book”* [CG1] and subsequently not being offered an appointment:

> *“I’m guessing that they just forgot me!”* [PT1]

The lack of communication regarding waiting list placement was *“incredibly frustrating”* [CG7], leading to feelings of worry as patients were not able to access treatments for their symptoms. A lack of communication caused confusion in services, who believed patients were already accessing treatments, leading to them not being offered treatment in a timely manner:

> *"...we hadn't heard anything as to when an appointment will be and I rang up last week, and they've gotten back in touch with me yesterday to say that they thought he was already seeing the psychiatrist…I said, 'No, we haven't seen anybody'. And she said, 'Oh, well, I'm not saying you've been missed off the list. But you're at the top, we already thought you were seeing somebody'." [*CG2]

Other patients and caregivers reported on their experiences of not being offered an appointment to treatment services once diagnosed, being told *"oh, yeah, she's on the list, blah, blah, blah"* [PT8]. Some found humour in being placed on a waiting list for years and not receiving an appointment, *"I've still not received my referral for the fatigue! [laughs]. I will still be on the waiting list!*" [PT1]. However, others were deeply concerned, or spoke angrily when reflecting on the lack of appointments:

> *"...there's one guy who comes along and sees [daughter A] for half an hour about once every six months, and he's just absolutely hopeless. It's just a complete waste of time. He said, 'maybe she could do music therapy', and he made a referral. This was two or three years ago, nothing's happened."* [CG8]

Lengthy waiting lists and not receiving an appointment in a timely manner led to some patients and caregivers accessing private health care. Some reflected on being in a fortunate position which allowed them to access private healthcare, as *"they had a plan…because everyone else just seem[ed] to be fumbling about"* [CG7] when trying to arrange suitable treatments. Caregivers focused on the difference between the waiting times in the NHS and private healthcare services, hypothesising that their child may have had much worse outcomes if they waited to receive NHS care:

> *"I don't know if we didn't have the option to go private whether the NHS would have eventually got their act together or whether [name redacted] would have never walked. I don't know which way round it is. My instinct is that possibly he wouldn't have ever walked."* [CG1]

These sentiments were not shared by participants who had the means to access private healthcare, with one patient finding herself in a difficult position with her health insurer, who delayed providing her with appointments and treatment options, and even involved the patient in seeking an appropriate healthcare worker to support her:

> *"So then I called my insurers and I said, 'I need treatment for FND'. And that was an uphill slog because they were trying to say that on my health plan, I didn't have it, they didn't have any people. Then they said, 'I needed to find somebody'.... All of this kind of stuff."* [PT6]

5.3.3.3.2 Barriers to accessing resources

Supporting the findings reported in Section 4.4.5, participants spoke at length of the barriers to accessing healthcare and resources. Many focused on how a *"postcode lottery"* [PT8] was in effect, causing patients issues when accessing appropriate care in a timely fashion, or being *"stuck [as] the GP had done all they could"* [PT3]. Healthcare workers reflected on their experiences of the postcode lottery, and how it affected their own services. One postulated how patients' were fortunate if they were referred to his service, as they were able to offer a variety of psychological therapies, whereas *"some people don't get anything"* [HCW1]:

> *"I think probably most places in the country are lucky to get anything other than CBT. We offer a few treatments and that's based on the experiences and training of the clinicians."* [HCW1]

To combat issues caused by a postcode lottery, some patients admitted to deliberately accessing services in other geographical areas, in order to *"have a better chance"* [PT9] when receiving care:

> *"Well… when I was first diagnosed, I went to my GP. But then, because my GP…I live like on the border of [town A] and [town B], my GP at the time happened to be on the [town A] side of the border. So I laid some groundwork, and I talked to my GP about it, but then, something to do with funding for the thing that I never had, the fatigue clinic, in [town B], I needed to be seen by a [town B] doctor. So I changed doctors and got the referral."* [PT1]

Issues in accessing services were not just caused by geographical location. Patients and caregivers experienced problems with being unable to arrange appointments, due to healthcare worker availability and training. Caregivers lamented how the person they provide support for was no longer able to access services, as the healthcare worker assigned to them had retired or was unwell, and therefore could no longer work with them. Others found that as soon as they were diagnosed with FND, they were unable to access the services already supporting them, as they did not *"specialise in it"* [PT5]:

> *"...[child] got transferred to [name redacted] children's services, they transferred [child] to a brilliant children's physio who we saw a couple of times and then she went off as she was about to retire."* [CG1]

These issues in accessing care were widely reported by both patients and caregivers, who also experienced barriers when attempting to access appropriate equipment and support to remedy their symptoms:

> *"When I asked questions about 'were there other options, can we tap into rehab, intensive physio or whatever', we were told, 'no you can't.'"* [CG1]

This experience was further supported by caregivers of children, who found that the equipment in paediatric physiotherapy services as unsuitable, as the equipment was too small. When discussing these experiences, the caregiver explained with exasperation that they were unable to use the adult equipment, because her teenage child was *"not an adult"* [CG1], leading them to access private physiotherapy and reflecting on how they felt let down by NHS services:

> *"...the private physio, we were paying the hospice to use the gym once a week which was lovely. But really not the way round things should have been done."* [CG1]

As well as being unable to access services and resources, patients experienced having *"no continuity"* [PT9] of care. Although some patients managed to arrange appointments and referrals, they were denied access to support as the doctor *"doesn't treat FND"* [PT8], leading to suicidal thoughts: *"who else could have helped me…there wasn't anybody"* [PT7].

Being passed from *"pillar to post"* [PT4] was a common feeling experienced by patients, who found themselves in a precarious situation when attempting to access treatment support. Patients were informed that their case was *"too complex"* [PT3] and had to wait over a year before being referred to a different service for treatment. They were also informed that they were not eligible to access therapy organised by charities as their PTSD was not linked to military service and were not allowed to use hospital transport as they *“don’t use a wheelchair or a stick”* [PT6]. Ultimately, these barriers led to patients feeling that they were *“the hot potato, in that they were always told ‘sorry, I can’t help you’”* [CG7] by healthcare workers.

As discussed previously, barriers when accessing healthcare led to some patients *“raiding all the[ir] finances [so they] could go private”* [CG1], leading them to spend *“quite a bit of money”* [CG5] on their care. Experiences of accessing private healthcare (in order to avoid the barriers in place in NHS services) were mixed, with some participants finding it was *“great”* [PT9] and *“really helpful”* [PT1], while others found their private healthcare appointments *“awful”* [PT7] and were unheard by the healthcare worker in their appointment.

Healthcare workers reflected on the barriers to accessing healthcare and resources, commenting on how MDTs can be a facilitator to improving access to care, as otherwise there is a *“gaping hole in [the] service”* [HCW1]. One healthcare worker was passionate in her description of the implementation of MDTs, that helped to better support FND patients, explaining:

> *“…we all want to work together to make it easier for these patients. The access to services for them is so poor, really, and I just think we want to see…well it’s the same for lots of conditions, isn’t it? But we want to do better for them, don’t we?”* [HCW6]

Supporting these thoughts, healthcare workers (who were part of an MDT) found that the approach *“seems to be the winner”* [HCW10] and that teamwork is *“just fantastic”* [HCW7], as FND patients need *“specialist services, specialist and multi professional people, specialist teams, people who have that experience or have that knowledge, the understanding. It needs to be one team”* [HCW8].

This theme highlights the importance of continuity of care, timely appointments and the utilisation of MDTs in healthcare. Patients were often placed on lengthy waiting lists, with some having to wait over two years to access support for their FND symptoms. While some patients and caregivers were able to access private healthcare, the experiences of private healthcare were mixed.

5.3.3.4 Theme 4: Life after diagnosis

Theme four describes how a patient’s (and at times, caregiver’s) life changes once they receive their FND diagnosis. Participants reflected on how they had to adapt to their ‘new normal’, accessing treatments and accepting the diagnosis and their new ‘label’.

5.3.3.4.1 Adapting to the new normal

Patients' lives changed dramatically after receiving their FND diagnosis, having to learn how to adapt to their 'new normal'. Many patients and caregivers focused on how they had to *"just get on with it"* [PT9], and learn to live with the condition and the changes it brought to both themselves and their family. Interestingly, patient and caregiver participants focused on discussing day-to-day activities rather than future goals, perhaps due to being unable to plan for the future, due to the unpredictability of FND and symptom severity.

The concept of learning to live with FND in this study is intriguing, as patients had very different mind-sets on what 'learning to live with FND' meant. Some participants accepted they were diagnosed with a chronic condition, and learned to live with their symptoms, whereas others felt they had learned how to live with their condition yet longed to return to their pre-FND life. A patient detailed an experience they had at a peer support group, where they had a very different mind-set to other attendees:

> *"Yeah, I was kind of there like, 'What help is there, is anybody doing anything that they've tried, what works?', and but a lot of them were like, 'well, this is just what we've got and you've just got to deal with it'. And that's kind of not my mind-set, but maybe that was just nothing to do with their FND. Maybe that was just a group of people and that was their mind-set. Yeah, I think maybe I'm just a bit different! [laughs]."* [PT1]

This difference in mind-set may be due to accepting that there is currently no cure or consensus to the best treatment options for FND. Therefore, patients learn to live with the condition, rather than feel frustrated or upset that they are unable to be cured:

> *"I think it's about for me what's helped and what's worked is, rather than getting frustrated that I can't get treatment and get rid of this, I'm learning to accept and live with it in the best way possible that I can."* [PT6]

> *"Aye. You just have to get on with it as best as you can. If you had seen me a year ago, maybe, I'd have been a bit more doom and gloom. This is what I have, these are the cards I've been dealt with. We do what we can. If you start feeling sorry for yourself and stuff… that's another thing."* [PT4]

Participants struggled to come to terms with the condition in the initial weeks and months after receiving their FND diagnosis before becoming *"used to it"* [CG4], finding it *"became kind of normal…life goes on and we just do the best we can"* [CG5]. Participants reflected on the initial difficulty and panic when they were first diagnosed and discharged from hospital:

> *"So it's like, we don't panic anymore when it happens, like I was panicking, everyone was panicking, like I had to get to bed but now there's times where you can feel the seizure coming on. I have you know, the pins and needles, but I describe it as like a slimy feeling that comes over my skin, my face, down my arms and legs. It's not like pins and needles, it's like a different, strange sensation."* [PT4]
>
> *"…it's been going on, you know, six years, you kind of get used to it. And in the beginning, I found it hard when he was…when he first came home from hospital, he was having multiple seizures daily."* [CG5]

Difficulty in understanding the disorder, and the unpredictability of its associated symptoms, meant that both patients and caregivers alike struggled to adapt and learn to live with the condition. Patients reflected sagely, stating that they understood why others feel that FND is a fake condition (due to the unpredictability of FND symptoms), and only learned to live with the condition once they were able to ready themselves for when their FND symptoms flared up:

> *"I totally get where people are coming from when they just think faking it or how, really, how can that possibly be happening? But when you're living through it…it's crazy. It's hard understanding it when you're living with it, it's because you can't get your head around it. You just learned to deal with it and be ready at any second for it to change."* [CG4]

These feelings of readiness and coping were reported by numerous patient participants. Patients reflected on how they learned to live with the condition once they realised that there was *"nothing profound, there's obviously nothing seriously wrong in the sense that it's something that was very progressive"* [PT9]. This helped them to cope and live with FND. Patients and caregivers alike felt that they had changed, due to having to adapt: *"it's…there's so many things that you just don't think about [that] you take for granted. And* *then one day you wake up disabled”* [PT6]. Transformations of who they perceived themselves to be before (and after) receiving their FND diagnosis was a focus of many patients, with many reporting changes to their physical and mental health, as well as changes to their personality. Comments were mixed, with some participants finding that they have changed for the better, whereas others felt they have changed for the worse. One patient participant, who was an NHS employee at the time of their interview, reflected on how he was no longer his previous self, due to his FND symptoms and negative experiences of accessing clinical services. This led him to grieve the loss of his previous self, while also giving himself encouragement him to change how he worked with his patients:

> *“I understand that is a grieving at the loss of your previous self. It’s not a gradual decline like what happens with age. It’s just…it’s taken away. It’s like bang! There’s the whole me but not me, but for me, that’s only about 30%, 35% of the impact. The biggest part of the psychological impact is dealing with the NHS, dealing with care workers who are supposed to be professional…they’re so judgmental…I think about the way I work with my patients, the way most of them, my colleagues work with patients…So that’s been a huge impact for me, yeah, it’s just beyond words at times.”* [PT8]

Poignant descriptions on the loss of their previous self, and how they struggled with their physical changes, were provided. Many patients struggled with this physical change as they *“used to be a very active person [but] now I have two sticks”* [PT3]. Indeed, one participant with young children reflected sadly on how they are now unable to play with their children in their garden without assistance:

> *“We have a wee bit of a garden here so I try to play football with [child], but there’s days I take the crutches out, days I take the wheelchair out when I don’t feel too great because I know I won’t be able to make it back in without falling. So when I’m on the crutches I try and take some shots with him. You’re not really walking about, he’s kicking it to you and you’re taking a few wee steps with the crutches and trying to interact with him that way but I feel for them.”* [PT4]

Interestingly, experiences of the clinical management of FND, and receiving an FND diagnosis, led to some personality changes in patients. While a minority appeared bitter when discussing their experiences, others felt more in control following their FND diagnosis, which allowed them to *“heal it better”* [CG5], enabling them to be more empathetic and have a better understanding of other people:

> *“I think also it works the other way in the sense that I’m much more understanding of other people. And if somebody hasn’t been around, rather than noticing people by the presence, you know, like my cousin, I noticed I haven’t heard anything. I haven’t seen her post anything on social media over the last 10 days. So I contacted her to see how she was and sadly, she has terminal cancer now, and she’s been in A&E a couple of times and been in [place redacted] for a day. So I think yourself being in a situation you realise if somebody’s not there, you think “they’re normally there. Where are they?”* [PT9]

One element of these changes included making adaptations to support themselves both in and outside of the home. Occupational health and physiotherapy teams were relied upon to support some of these adaptations, providing crutches, wheelchairs, rails, chairs, and perching stools. These adaptations allowed patients to feel safe and secure in their homes, as well as ensuring they were still independent:

> *“In the house I have my two crutches beside me. I have a wee perching stool from the OT [occupational therapist] for trying to do dishes and stuff in the kitchen. I had a wheelchair from the Red Cross for a while when I realised my legs weren’t getting any better for hospital appointments. I got one from the OT eventually, he measured me up for one and I’m quite tall, so they measured me up. I have my crutches and I try and walk without them, but whenever I try and walk without them, I’d fall, the balance is off and I’d tend to go over to the right side when walking up the hall. There’s times where I’d use one crutch, but if I’m going into hospital appointments we’d bring the wheelchair as it’s too far to walk, even with the disabled spaces and stuff.”* [PT4]

Although some patients and caregivers utilised equipment from the NHS and charitable organisations, others were more creative. Caregivers created *“seizure first aid kits”* [CG7] and *“go-bags”* [CG4] so that they had the equipment needed at hand, whether at home or in public. Others developed their own easily accessible documentation (worn on a lanyard), which explained FND and their symptoms, along with what to do in an emergency if they had a seizure in public:

> *"We've got a lanyard that she wears. So if she's having a…you know, it like explains what to do if she has one because like, I know the protocol is to call an ambulance, isn't it if someone has a seizure? And I'm like, "no, no, no, don't do that" [laughs]."* [CG7]

Further adaptations included using *"hiking sticks"* [PT3] to keep themselves mobile and buying a *"second hand sit-on buggy so that at least [they] can get out there"* [PT9]. Others sold or traded their car due to safety reasons:

> *"If I had a seizure while trying to drive…if I hurt [myself] or somebody else I couldn't live with myself."* [PT4]

> *"We try to get her in the back [of the vehicle], but when she's paralysed, you can't get her in because she's just too floppy and you can't get your angle to get her in. And then she has another one where she freezes on her tiptoes. But she's really…her legs are massively long, and so we've had to swap, we've swapped in time before that happened, but we've got a transit van now with the sliding doors so we can get her in and out and she can get herself in and out even when she's paralysed because it's got the little bit where you can, she can jump out of the wheelchair onto the seat and then get herself up onto where she's meant to be sat".* [CG4]

These adaptations were important for both patients and caregivers as it allowed them to have some independence, while also ensuring their safety.

5.3.3.4.2 Treatments: the road to nowhere

After receiving a diagnosis, the next natural step is to consider potential treatments or interventions. The experiences of accessing different treatment options (to alleviate FND symptoms) were a major focus throughout many of the interviews. Participants perceived the attempt to access treatment options as a 'road to nowhere', where they were unable to access the support they needed, due to waiting times or not being referred to appropriate health services. This led to some participants deciding to take matters into their own hands by arranging their own treatment, implementing coping strategies or self-managing their symptoms. Participants discussed patients' readiness for treatment, and how at times they would avoid accessing healthcare.

Similar to the findings detailed in Section 4.3.8, psychological therapies, medication and physiotherapy were the most reported treatments that were accessed by patients or offered by healthcare workers. Most participants, who had received psychological therapy (such as cognitive behavioural therapy [CBT]) or counselling, were sceptical at first, *"what's counselling gonna do? How's it gonna make it any better?"* [CG4]. These initial apprehensions were alleviated once they embarked with the treatment, as it equipped them with coping strategies and assisted in *"sorting out thoughts, feelings and emotions"* [CG4]:

> *"I still think the best thing we ever had, throughout all this was the first psychologist just given those grounding techniques. I don't know where we'd be without that, because he'd be on the floor practically every time. It just stopped him going to that extent, you know, so that's been really, really good."* [CG5]

Medications were prescribed for pain or mental health conditions. One participant struggled to access the pain medication prescribed by the neurologist, as a nurse practitioner stated their symptoms were *"just normal aches and pains"* [PT8] and refused to hand over the prescribed medication. Another was prescribed medication as they became depressed, due to the severity of their symptoms. Lastly, physiotherapy was found to be helpful, as they offered tailored interventions and *"really cared"* [CG2]:

> *"They were very good at tailoring things around me...they took time to explain the exercises and what they hoped to achieve."* [PT2]

Although many patients were willing to undergo treatments as soon as possible to alleviate their FND symptoms, others commented on their (or in the case of healthcare workers, their patients') readiness to receive treatment. Indeed, an ambivalence towards accessing psychological services was noted throughout the interviews, with patients feeling unsure why they needed to attend their appointment yet still did, due to wanting to "*give it a go"* [PT10]. This ambivalence towards treatment may have also developed due to the patient's experiences when accessing diagnostic services.

Healthcare workers persevered to support patients and contain their distress while determining their readiness for treatment. While it was *"frustrating"* [HCW8] when patients did not want to be supported, healthcare workers acknowledged it was their decision to access support:

> *"...the other one hasn't been referred, [he] didn't want further support from me and [was] subsequently discharged. I do think that they needed that support, but that's their decision. I can't."* [HCW8]

> *"You know, and just for me as a person, working across neurology, but that's what I, you know, I want to impart to my patients is that I'm passionate to help them, but I can't do it for them. So I'll do everything within, you know, within the scope of what I've got in facilities and resources in terms of time and everything, of course, to give them, but they've got to want to do it too."* [HCW6]

The need to address other physical and mental health concerns impacted patients' readiness for treatment to improve their FND symptoms. Healthcare workers utilised a person-centred approach to care, and worked with patients to determine whether they had other pressing concerns or priorities they needed to be addressed first, as otherwise the treatments offered by their service would not be beneficial. These decisions were *"really hard"* [HCW2] for healthcare workers to make as they did not *"want to let [patients] go"* [HCW8]:

> *"I saw a lady who had non-epileptic attack disorder. That was what she was referred to us with. And she also had kind of really bad migraine type headaches. And when we did the assessment and formulation, and we kind of talked about what her priorities were, actually the thing that was more debilitating for her at that point was the headaches rather than the seizures. And so what her priority was, was to do some work around pain management tools to help with that."* [HCW3]

While acknowledging that patients may not be ready for treatment at the time of their appointment, healthcare workers ensured that they knew they would be able to return to the service, "*you know where we are, and you can come back if you need [to]"* [HCW1]. This allowed for patients, who were initially *"very angry and upset"* [HCW9] about their experiences of accessing services when receiving their FND diagnosis, to have *"time to reflect"* [HCW9] and access treatment support. One service demonstrated innovation in treatment care via implementing a patient-initiated follow-up (PIFU) pathway, ensuring patients would not need to be re-referred and *"slip through the net"* [HCW6]:

> *"...[we] recently, probably in the last 12 months or so, started a patient-initiated follow-up, so a PIFU for patients…So, on the whole, anybody who's just not quite*

> *ready, I'd say to them, "right, let's think about PIFU, should we say three months, we say six months, I'll give you a call then, see how things are. In the meantime, here's our contact details. If you think, right, I'm ready now. Get in touch, we'll sort out an appointment". And it seems to be working really well with all of our neurology patients, because they've all got long term conditions, haven't they? So it's working really well with all of our neurology patients, but it is a really nice fit for the FND ones as well."* [HCW6]

Mirroring findings in Section 4.4.2, survey respondents were unable to access treatments, as they were not offered either a follow-up appointment or referral to appropriate health services. Patient participants experienced being discharged from hospital without being told *"what [they are] going to do"* [CG1] next; they felt *"angry"* [CG3] and *"completely demoralised"* [PT9] at the lack of follow-up:

> *"...no one was trying to help him or suggest like writing things down or anything. He was just told, "Yeah, you've got FND, and you can basically go home". And that was it."* [CG2]

The lack of follow-up appointments and referrals to services caused led patients and caregivers to take matters into their own hands and attempt to arrange appointments themselves by *"banging on the door and being a pain in the backside"* [CG3], or researching in *"great detail to what other people have done and…what worked for them*" [CG6]. Several patients and caregivers spent time researching potential treatment options, and then requested for their GP to refer them to the appropriate services. Throughout the interviews, participants became frustrated when explaining how they had to repeatedly attend GP appointments in order to arrange treatments, while also feeling dismayed or angry at the thought of their GP not instigating referrals:

> *"...it's not down to us to ask for prescription medication. It's not for us to ask for speech and language, it's not for us to be asking for…They should be saying, 'okay, you've got this, how is it impacting and what can we do to provide support?' and discuss it with us. And then do the referrals. Not us as the patient or even the partner, actually going 'excuse me, can I have a speech and language referral please?' And they question us, 'why?' 'Because his speech and language is affected, he's losing the ability to talk, it's one of the classic symptoms'. 'Oh, Okay'. 'Excuse me?!' [laughs]."* [CG3]

Alongside treatments offered by services, patients utilised self-management techniques to manage their FND symptoms. Patients implemented their own physiotherapy programme to teach themselves *“how to walk again”* [PT8], and one even took up the piano, as they had heard that it *“can help connect the sides of the brain”* [PT9]. Other participants learned meditation, mindfulness and grounding techniques in order to *“keep them in the moment”* [CG5] and stay in control:

> *“I’ve got more resources and using those sort of distraction techniques to stop it from happening. And, and I’ve learned to control things. You know, I know when I’m starting to get tics. I think, “okay, get up and do something else” or, you know, hopefully I’ll maintain that ability.”* [PT9]

Complementary medicine options were also used as self-management techniques, with one patient receiving massages and undergoing hypnotherapy to improve their symptoms, as they were unable to take prescription medication. Lastly, a small number of patients were self-medicating to reduce their symptoms, which led to mixed outcomes:

> *“..he likes to have a gin or several gins, and then if something has particularly happened, then he’ll get quite tearful.”* [CG2]
>
> *“...he has started taking CBD [Cannabidiol] oil, which has had quite a significant impact on improving his hands, his ability, his cognitive…Because he was leaning to the right and would sit in his chair and be like that [demonstrated lean]. And when driving, he would veer, and I said ‘you’re not driving anymore, mate’. But since taking the CBD oil that side of it has disappeared”* [CG3]

This self-medication may have been one of multiple coping strategies employed by patients when they were unable to access treatments. Coping strategies featured prominently when discussing life after receiving the FND diagnosis, with many participants using laughter to cope with their ‘new normal’. When discussing the utilisation of laughter and inappropriate jokes as a coping mechanism, patients’ and caregivers’ demeanours changed during the interviews, becoming much more jovial than when discussing other experiences*; “you know, one has to laugh at these things”* [PT7]. Interestingly, laughter and inappropriately joking brought caregivers (and the person they support) closer together, as they had developed their own inside jokes:

> *“...you know, he does laugh quite a bit about it. We both laugh because he does sound you know…we both say he just sounds ridiculous. You know, between him and me we can laugh about it.”* [CG2]

> *“What she does is she will always look to the right. And you say, ‘we’re over here’, she says, ‘I know’. She just won’t look at you. And you say something like…it’s funny. So you say sometimes, this sort of joke, ‘look at me’, and she will take her glasses off, she’ll be looking like that. She’ll take her glasses off and go like that [demonstrating moving the glasses] [laughs].”* [CG8]

Lastly, the deliberate act of not accessing healthcare was discussed by all three population groups. Although it would be prudent to assume that the reasons for avoiding healthcare may be due to an inability when accessing treatments, or negative experiences of attending services during the diagnostic journey (both discussed throughout this chapter), patients decided not to access healthcare support when needed due to not wanting to waste hospital resources, or determining that their symptoms were not serious enough to warrant a trip to A&E:

> *“I’ve never really bothered to go back to hospital even whenever I had different things happen. I’ve just kinda…I mean, I wouldn’t recommend it, but for myself, I’ve just gone “oh, well, this is just FND. And it’s not going to kill me. So let’s just stay at home”, which I guess is not really what you’re supposed to do.”* [PT1]

> *“I mean, I now know, just don’t go to A&E unless I’ve injured myself. Don’t send me there, there’s no need. It’s a waste of resources and time.”* [PT9]

Healthcare workers discussed patient attitudes towards the avoidance of accessing healthcare, with some being *“pervasively hopeless”*, leading to *“patchy engagement with attendance at appointments or non-engagement”* [HCW3]. These attitudes were prevalent in a small number of patient and caregiver interviews, with one patient not pursuing cancelled healthcare appointments to be rescheduled, due to the hopelessness of her situation “*It’s just kind of like, ‘what difference will it make?’ She’s been beaten, unfortunately”* [CG6].

In addition, healthcare workers” perceived lack of knowledge, awareness and attitudes about FND caused patients to avoid accessing healthcare. One patient felt victim-blamed and invalidated when being assessed by a neuro-psychologist, leading to her refusal in attending any further appointments, *“I decided I don’t want to have therapy with her, and I’m still having therapy with my therapist. But she, you know, has never heard of FND and you know, can’t treat it”* [PT8]:

> *“Yeah, anytime…well, I’ve been in an ambulance a few times now in that situation, they don’t know what to do and they don’t know what FND is…But generally, you’ll find that it won’t be the first thing that I tell them, because…they also get oh… what’s the word? They can sometimes treat you differently if you say you’ve got FND. Of course, it didn’t used to be believed as an illness. So now, at any point if I’m not well, I would do my utmost to not end up in hospital because of that situation.”* [PT3]

> *“There’s so much stigma around FND, that in my head I would think ‘well hang on a minute, is this doctor going to help me, or is this doctor just gonna think that it’s a made up disease that I don’t really believe in’, which is why we’ve just not been. And as I said, luckily enough, my gamble paid off and I’ve not needed to go to the GP.”* [PT1]

5.3.3.4.3 Accepting and believing the ‘FND label’

As discussed in Section 2.6.4, patients may not readily accept their FND diagnosis (or the FND label) for a myriad of reasons. Although this is a shorter sub-theme compared to the others presented in this chapter, it is still worth reporting on the experiences and perspectives of patients accepting their FND diagnosis, as it has been reported in previous research that patients who do reject the diagnosis face poorer clinical outcomes (Fouche et al., 2019, Rawlings et al., 2017).

Beliefs about chronic or confusing medical conditions, stigma from healthcare workers, their family or the public may impact on the readiness of a patient to accept their diagnosis. Participants reflected on the FND diagnosis and the acceptance and beliefs surrounding it. Healthcare workers reflected on the potential reasons why a patient is more likely to accept their FND diagnosis, with others focusing on the role of shame and negativity:

> *“I think it depends on how well that initial explanation can be done, what their previous experience is of maybe other encounters they’ve had, and how other clinicians have dealt with it.”* [HCW10]

> *"I think people…they might be given a diagnosis, but it's very hard to accept as there may be shame attached to it and all sorts of other negative things attached to a diagnosis like that."* [HCW7]

Indeed, providing a well-thought-out and thorough explanation of the condition (during the medical appointment) led to more patients accepting their diagnosis, as *"people just want an answer…they want something that makes sense"* [PT1]:

> *"…So you're not doubting yourself quite so much. So that that was really useful. It was tremendously useful. But as I've had with the neurology here, they confirmed the diagnosis, and basically simulate 'it says in there, the MRIs show no damage', which I know is the case with FND."* [PT8]

Other patients felt that they had no other choice than to accept the diagnosis, stating, "*I suppose I am accepting of it. Because I haven't got any other choice, have I? I just gotta get on with it! [laughs]"* [PT1]. Despite receiving ample information during the diagnosis appointment, some participants attempted to find other diagnoses for their symptoms, before accepting their FND diagnosis:

> *"[I] would be looking up things on the internet, 'oh I could have this, I could have that', but you've been told this is what it is. So, in my head, 'this is what I have, this is what you have to manage."* [PT4]

Once receiving their FND diagnosis, patients struggled to come to terms with healthcare workers not accepting that their symptoms were related to their FND diagnosis, and did not believe it was a 'real' medical condition. One patient (who is employed by an NHS Trust) was warned of these beliefs when they first received their diagnosis:

> *"'You're in for a rough ride with this because there's a lot of people that don't accept it's real'. And I still didn't know what he was talking about. So then I was trying to get a fit note because I couldn't walk properly. And I spoke to three different GPs at this practice over several days and they wouldn't give me a fit note. They told me it was a psychiatric condition. They said that I was looking for time off work. One of them actually said to me - this is all over the phone because this is when COVID was at its peak - one said he thought I was malingering."* [PT8]

This frustrating experience was reported by other patients, who had found that healthcare workers did not accept their FND diagnosis, believing that they were *"faking it"* [CG4] and found it difficult that *"the people you go to for help don't believe you"* [CG4]. These feelings, accompanied by an acknowledgement of the general lack of awareness and understanding of FND, led to some patients becoming concerned that receiving an FND diagnosis is a negative label. Concerns of being labelled was mirrored by one healthcare worker, who reflected that *"sometimes it's not good to have that diagnosis because you're almost labelled"* [HCW8]:

> *"You know, it's because it's still a label that people sort of see it as 'functional neurological', that doesn't mean anything really, does it? It just means something's wrong with you but [healthcare workers] don't know what it is"* [PT9]

From this theme, it is clear that learning to live and adapt after the FND diagnosis is a difficult process for both patients and caregivers. Patients struggled to accept their diagnosis, finding themselves grieving for their previous, active lifestyle. While occupational health assessments were completed to adapt patients' homes to ensure their safety, treatment access was often seen as a 'road to nowhere', due to not being referred to appropriate services. This led to patients and caregivers developing their own coping strategies and treatment plans to lessen their FND symptoms. Lastly, innovation in treatment services was demonstrated by some healthcare worker participants, who worked alongside patients to determine their readiness for treatment. This innovation is an important development in the clinical management of FND, as it encourages patient-centred care, which is an essential component to a high-quality service (Care Quality Commission, 2022).

5.3.3.5 Theme 5: The Impact of Functional Neurological Disorder

This final theme comprises the participant perspectives of the impact of FND. Participants explained their experiences about how FND not only impacted their own livelihood, mental and physical health, but also their loved ones and friendships.

5.3.3.5.1 FND's impact on the self

All 10 patient participants observed how their FND diagnosis and symptoms impacted them, whether physically, mentally, socially or on their livelihood. In contrast to other participants, one patient reflected on how their healthcare worker warned them of the unpredictability of FND symptoms, and explained how her husband was happy that her symptoms have lessened since the time she was first diagnosed:

> *"…it was like a bit of a rollercoaster to start with, my symptoms did change, which actually Dr [name redacted] did say that your symptoms wouldn't stay static…they did morph a little bit... one minute being able to walk, the next minute not been able to walk. And getting upstairs was like climbing Mount Everest every single day! And on bad days, my husband used to have to drag me to the toilet, which it's not something you want to do for your wife, is it? He's glad those days are over! [laughs]."* [PT1]

This unpredictability of symptom occurrence and reliance on family members was corroborated by caregiver participants. Caregivers expressed how major changes to their home (or way of living) had to be implemented in order to help support the patient and their symptoms, stating they *"slept in the lounge"* [CG7] to lessen the chance of themselves or the person they support being injured due to their FND symptoms. Interestingly, caregiver respondents focused on how symptom onset was unpredictable, leading to feelings of isolation for the person they care for. This indicated that these feelings of isolation may also cause FND symptoms to worsen, or be exacerbated when they attended social events:

> *"But now it's, yeah, I mean, she has no friends, because she's moved to high school, a different one to everyone else that she was at school with. So she doesn't see any of her primary school friends. And she's not been in high school long enough to make friends with her one week at school."* [CG4]

> *"…he won't go to weddings, he won't go to parties, you know, it has a massive, a massive impact, you know, on your life. Because you just don't know when it's gonna happen [laughs]. That's the hard bit about it, if you knew you're gonna have a seizure at six o'clock in the evening, you could do everything lovely before that, couldn't you? But you just don't know, when it's gonna happen, yeah."* [CG5]

> *"…when he's really anxious, like at this work party we went to. When he first got there, because there's like 300-400 people there, his arm starts really shaking and his leg really shakes on his left side. But that, as I say, doesn't last long, and it will go but I think 'God is the potential there for something else to kick in?'."* [CG2]

Not only was the unpredictability of when symptoms would occur discussed, but conversations were also held on the unpredictability of symptom severity. One patient observed how this unpredictability first caused him and his family to panic, whereas now he is at ease when his seizures occur:

> *"…so it's like, we don't panic anymore when it happens, like I was panicking, everyone was panicking…At times it goes really mad straight away, whereas other times it's like a wee, a wee tiny shake of my legs and it goes frantic. Erm, other times it goes frantic straight away. There's other times I don't feel anything and I start shaking, you know, really, really violently shaking so it is. I have the tremors every day, what I call my normal wee shakes but the seizures, they're not so frequent but they're still every…I'll have one at least every day. But it's not as constant, I'm not panicking. I just try to work through them more."* [PT4]

The impact of FND on independence and isolation appeared to go hand-in-hand. Both caregivers and patients reflected on how FND impacted independence, particularly on their ability to leave the house alone. Patients lamented on the loss of their independence due to no longer being allowed to drive, whereas others focused on the potential of causing harm if they drove a car:

> *"Because he's scared to go out walking by himself because he has drop attacks."* [CG3]

> *"I only sold my car at the start of this year. He said don't give up on it, but if I took a seizure while I was trying to drive and hurt myself or somebody else I couldn't live with myself. So I knocked that on the head."* [PT4]

> *"Yeah, because he had to give up his licence because obviously it wasn't safe to drive and that's been very hard for him you know, it's very hard because of your independence, isn't it?"* [CG5]

Interestingly, one patient brought up a thought-provoking point on worrying about completing typical day-to-day tasks, which was not discussed by any other participant or population group:

> *"I have had a dentist appointment and I just had to take loads of clonazepam because…yeah, I jerk. It was things like bikini wax, how do I take care of my like, just general care? Barber? Is it safe for me to have my head shaved or razor*

> *anywhere, like when I’m jerking? So I didn’t, I didn’t cut my hair for ages. It was just like, there’s so many things that you just don’t think about you take for granted.”* [PT6]

Patient respondents believed that their FND diagnosis (and subsequent symptoms) impacted on themselves as a whole. They mourned the loss of who they were previously and having to adjust their thinking to ensure they did not harm themselves. Interestingly, two participants, who were mourning the loss of their previous selves, were of a similar age and gender, and had a similar time of diagnosis. One was much more accepting of this loss, even joking and laughing when talking about their lived experiences, whereas the other patient had a defeatist attitude and was very despondent. This was perhaps due to the variability of their symptoms, as the more jovial patient experienced mobility issues, yet was still able to work, whereas the despondent patient had to medically retire due to speech and mobility issues:

> *“I’m not who I was before. That’s gone. Everything about me from before has gone.”* [PT2]

> *“There’s the whole me but not me…And this is… what I find difficult is I’ve lost a lot of muscle mass. I can’t do stuff. I still work out, but now I’ve got to do it by perceived exertion.”* [PT8]

This feeling of mourning their past self may stem from the physical and mental impact of FND. One patient participant observed how FND had caused severe memory loss, leading them to forget events which took place before their diagnosis:

> *“…my memory is very hazy, you know, things keep popping up my phone from 2019. I had no idea I’d been to Prague. No idea I’d been to Greece in 2019. I had no memory. Photos didn’t jog anything. So, there’s a lot that’s gone.”* [PT9]

It is perhaps not surprising that participants felt that FND was detrimental to their livelihood. Patients were forced to give up their career or retire earlier than they wished; this in turn caused strain on their household finances. Throughout the interviews, patients reflected on their lack of willingness to access benefits, and focused on how they wished to have a job or be back at their career:

> *“I’ve lost everything now. I don’t know where to go from here. I’ve gone from £60,000 a year to £63 a week. It’s a disaster.”* [PT2]

> *“People say about malingerers, I’ve not had a penny, but I can’t work and I’m dedicated to my career and you know, miss it.”* [PT9]

Some patients and caregivers described how this lack of employment led to depression and frustration and lamented on how FND had considerably altered their life goals. These feelings were supported by comments from healthcare workers who discussed how their patients felt *“depressed being off work, because he felt he’d let his family down”* [HCW2]:

> *“But yeah, he has been engaging, he wants to get better. You know, he wants to be working... He doesn’t want to be ill and dependent. He’s a very proud man. It doesn’t sit comfortable claiming benefits.”* [CG3]

Those willing to access benefits and government support observed how it was *“game changing”* [CG7], as it allowed them (or the person they support) more independence and reduced their worrying and anxiety. However, many participants struggled accessing support, while others were concerned that their benefits may be amended or revoked:

> “*I’ve got PIP [Personal Independence Payment] at the minute but they’re reviewing my PIP.”* [PT4]

> *“So he got standard daily, when in fact, it should be enhanced daily. But we’ve got an award. And you don’t argue with it, because you run the risk of losing it.”* [CG3]

> *“And you’ll laugh at me now, but woe betide them if they take that of her, because I’ve said to them, ‘you know, if you take this [PIP] off her now, and she makes another attempt on her life, then I will hold you totally responsible, because this is the only thing that is making her life worth living at the moment’.”* [CG6]

Lastly, the impact of FND on education was disclosed by a small number of caregivers. Caregivers commented on how their child felt “*frustrated”* [CG4], as they missed so much school due to their FND symptoms, and wanted to attend lessons as they were worried about falling behind their classmates:

> *"But I think it doesn't help because she's frustrated because she wants to go back to school because she's very intelligent and she loves school. And she hasn't been able to go. I think that's what's triggering the problems at the minute because they're doing all the end of year tests ready for next year. And she's getting frustrated that she knows she should be in the higher classes. But she can't do the test because she's not there. And even if she's there, she's struggling because she's missed bits of work and stuff."* [CG4]

> *"…She didn't want to drop a year, she said, 'I've lost enough. I want to do it'. 'If you want to finish then you need to be in school'. So we trimmed her timetable back, we dropped subjects, she came home for lunch, we did as much as we could to make her just be in for those lessons."* [CG7]

5.3.3.5.2 FND's impact on the family unit

Interviewees revealed how the FND diagnosis and associated symptoms impacted their familial relationships, with some reporting it *"massively affected our lives"* [CG5]. Participants worried about the financial impact of FND, particularly their life insurance *"if I die here…will [my] wife be covered?"* [PT4]. Others observed how their relationship roles had shifted since receiving the FND diagnosis:

> *"You know, our life was very much, 'I was going to be paying our mortgage off'. We were like three years…because we were overpaying it and I was gonna retire. And he'd always said 'no, he didn't want to, you know, I wouldn't have anything to do'. Whereas I was, you know, I couldn't wait to leave work. And now our roles are totally reversed. He's sat at home with the dog [laughs], doing something he doesn't want to do. And I'm…I'm at work, still doing what I don't want to do. You know, it's really just changed everything."* [CG2]

Changes in family dynamics were highlighted by many participants, especially those who were providing support to their child who had received the FND diagnosis. Caregivers reflected on how they were also *"living it 24/7"* [CG7] due to the large amount of support they provided, and how the condition impacted their housing arrangement:

> *"I had to sleep with her you know, just because if she had one and she wasn't breathing, I was on scene, I'd hear that, you know, that sort of thing. So that's why we slept in the lounge, so we could be together, and I'm talking mattresses on the floor, because there's no way I'd have stuck her on a bed…I would say yeah, that*

> *definitely affects the family. The whole family, yeah, as well as obviously the child themselves."* [CG7]

The change in family dynamics not only affected adults, but also children. Participants reflected on how resilient the children in their nuclear and wider family were. Although most comments were positive, such as how it was now *"second nature"* [PT4] and "*it's just another part of [their] lives"* [CG4] to their children, participants lamented the difficulty of the condition's impact on their children:

> *"I feel for the weans, the kids, the wee boy is [age redacted] and the wee girl is [age redacted]. The wee girl didn't remember me ever taking her anywhere, you know, driving, or going to go play or have fun or whatever. "Daddy you've always shaked [sic], you've never been able to take me anywhere'."* [PT4]

Patient participants focused heavily on the detrimental impact FND had on their romantic relationships, commenting that their partner or spouse get *"very emotional"* [PT4] due to the pressure and stress caused by the disorder, and how it was a major factor in damaging or ending relationships:

> *"Yeah. And I just got divorced this year, after 20 something years, so you know, there's a lot…there's a lot going on. And it's very difficult for everybody."* [PT3]

> *"…it's also having a major impact just on a personal relationship level…And it's not like we're married, which you know, better for worse, in sickness and in health scenario, we don't have that, we're not married. So it is changing the relationship, which is not brilliant. It's not what we want."* [CG3]

While FND had a negative impact on personal relationships, one caregiver's account highlighted how the condition led to rapport building between healthcare workers and the patient, and also between the healthcare worker and the caregiver. After supporting the person they care for in hospital, the caregiver found herself in a particularly candid situation, where a healthcare worker spoke to her privately after her husband had recently received his FND diagnosis. This conversation provided an insight into the awareness of healthcare workers, regarding the strain FND can place on both the family unit and on caregivers:

> *“She said to me, this is just before he was discharged. She said ‘Get on with your life’. That’s what she said to me. And I had no idea what she meant at the time. But by heck I do now! [laughs] That was, that was quite revealing, really*!” [CG5]

Caregivers commented on how FND had impacted themselves, as they felt *“frustrated”* [CG2] and *“distress[ed]”* [CG5]. Others reported having to receive physiotherapy due to the injuries they received while caregiving:

> *“…actually in catching her so much, I ended up in a pelvis brace because I pulled my back catching her. So I’m now out of it, but that was just luck. There’s not much of her, she’s not heavy but a dead weight is a dead weight.”* [CG7]

The impact of FND also affected caregivers’ mental wellbeing. Caregivers were hesitant to discuss their mental health in relation to providing support to their loved one with FND in real life as well as in the interview setting. Some commenting that they *“put on this act…that everything’s fine”* [CG2] while acknowledging it is not a healthy long-term solution:

> *“Yeah, I do feel like that. Yeah, I do feel like that. Yeah, I just try not to cry.”* [CG2]

> *“Anyway, after about five days, I literally went out to the car to buy her a cream… I just wanted any excuse to get out of there. And I sat in the car and I cried solidly for about an hour and a half, because I just didn’t know what to do.”* [CG6]

> *“I don’t know. It’s just if it was affecting my health which at the moment it’s…physically it’s not, mentally it’s…I don’t know.”* [CG3]

5.3.3.5.3 Impact on friendships

Unsurprisingly, FND impacted on friendships, with patients not being physically able to socialise, or patients and caregivers feeling too overwhelmed to be able to attend social events. The FND diagnosis and symptoms gave participants a rare opportunity to compare their current friendships and reflect on whether they were fair-weather or a good friend. One patient found herself surprised at the friends who stuck by her after her diagnosis, and explained how the disorder even strengthened their friendship:

> *"…I realised that we went out for lunch recently. And it's one of those situations where people are listening, not to understand or hear, but to, say their own conversation. And, and things that yeah, I just think this is such a super superficial conversation going on. And they're the ones that say, 'Oh, I can't play', 'Oh, can't you? Oh, that's shame. We won't ask you', then move on. You know. So some friends have been…you found out your superficial ones that don't really offer you lifts. And there have been other people who, because obviously, I had a long period of not driving would say, 'we'll pick you up'. And from surprising friends. So I think in a way it's broadened my friendships in the sense of, I don't just stick with those one or two people that I've always got on with. I, I see more people as people that are friends and get to know that, that I probably wouldn't, because they're not in my little clique or my age group, you know. And so I think it's opened up…people that I like, and I think like me for who I am, you know. So I think it's probably done that, because some friends they're just, you don't see them."* [PT9]

Realising the worth of friendships was observed by many of the patient participants. Interestingly, patients discussed their friendships very differently from one another, with those who received their diagnosis years before the interview took place talked in a much more forgiving and joyful tone than those who had only been recently diagnosed with FND. This was perhaps because they had more time to reflect on their friendships, and accept and grieve the end of them:

> *"It's a great way to spring clean the friendships [laughs]!"* [PT9]

> *"And also this year, it's been a real sort of sifting of friendships like, I now know the core people that absolutely, you know, are worth all of my time. Yeah."* [PT6]

> *"Yeah. Yeah I've been very, very hurt by it. I have been hurt people that I thought were my friends."* [PT9]

Some participants reported how their friends felt uncomfortable about their diagnosis, and then sadly avoided them. These experiences correspond to the findings reported in the scoping review, where FND patients experienced negative attitudes and a lack of understanding, from both proximal and distal individuals (Rawlings et al., 2017):

> *"With some of [name redacted]'s friends, it was more…they couldn't deal with it. That's not helpful. You know, obviously, her being in it…they didn't want to be near her."* [CG7]

> *"And we had seen sort of friends out and about some people are a bit, you can see they're a little bit uncomfortable."* [CG2]

The FND diagnosis also impacted information sharing and conversation topics. One caregiver reflected that her and her husband disclosed to some close friends that he had epilepsy rather than FND, because *"that's recognised, you know"* [CG5], revealing that it was easier to say. Interestingly, instead of using FND as a bonding opportunity, another caregiver admitted that she avoids conversing with her friend in a similar situation, so as to preserve the friendship:

> *"I do have [a] friend who I've not really talked about it with since I know that's what their daughter had. She had non-epileptic seizures about ten years ago and they really struggled with accepting it…they really didn't handle it at all well. 'It's all in your mind, snap out of it' kind of attitude. So we're still really good friends but we don't talk about it between us [laughs]."* [CG1]

5.3.3.5.4 FND's Impact on healthcare workers

Lastly, the interviews revealed the impact of FND on healthcare workers. Healthcare workers felt immense pressure when supporting FND patients, worrying about the potential impact of either not delivering a diagnosis, or delivering an incorrect one:

> *"With functional speech disorder, it's terrifying because I think 'what if I got it wrong? What, what's happening? What's the impact?'."* [HCW8]

> *"But my worry is that she doesn't have a diagnosis. So if, and it's, you know, it's quite possible she has another episode of this, who does she go to then? You know, I've let her GP know as well, what I think is going on."* [HCW2]

Healthcare workers also reflected on the pressure of failing a patient and their needs. Healthcare workers described going above and beyond their duties to support FND patients as they were aware of the limited support available and how *"they need* *someone"* [HCW8], while struggling to accept that sometimes they were unable to provide further support:

> *"I'm doing what I need to do for our patients, because one, they deserve the service. And two, they need somebody. Okay, they've been landed on me. I don't know a lot. But I'm, I'm going to do my best and try and help them."* [HCW8]

> *"…I think sometimes you have to learn to understand that it's not a win-win with everybody either. And I got to the point with [a patient] that I knew I couldn't help her any more than everything that I tried to do with her, she was totally unable to tap into any relaxation method, she just couldn't do it…And it feels really sad and it feels sometimes, like you've failed, but you also have to learn that you can't make everybody better, no matter what you suggest, or do with them."* [HCW2]

From the information provided by participants, FND has an immensely negative impact, not only on the patient, but also their family and loved ones, as well as the healthcare workers involved in their care. The experiences of the impact FND has had on patients were overwhelmingly negative, with patients sharing insights into their loss of independence and livelihood due to having to give up driving or their career because of the severity of their symptoms; this led to a detrimental effect on their mental wellbeing. While some friendships were developed or strengthened, the majority of pre-existing friendships and relationships suffered or broke down due to the unpredictability of symptom severity, or from individuals feeling uncomfortable because of the diagnosis.

5.4 Discussion

This study aimed to explore the lived experiences of healthcare workers, patients and caregivers on the clinical management of FND. Twenty-eight patients, caregivers and healthcare workers (based across the UK) participated in the study, providing their experiences of the clinical management of FND. Patients and caregivers spoke at length about how FND impacted all areas of life, and how they learned to adapt to their 'new life' after receiving the FND diagnosis. Healthcare workers highlighted the importance of collaboration and communication, whether it be with patients, healthcare workers or other NHS services. The implications of this chapter are in relation to the survey study's research aims and objectives. Recommendations for the clinical management of FND are considered.

5.4.1 Potential triggers for the onset of FND

One of the objectives of this study was to explore the potential reasons for the aetiology of FND. The majority of participants believed that trauma (psychological or physical) was a potential trigger, followed by stress along with emotional problems and issues. These beliefs follow the existing literature, reporting that psychological and physical distress are common aetiology of FND (Fobian and Elliott, 2019). As discussed in Section 1.4, research is now starting to focus on the potential link between the immune system and inflammation response being a potential reason for the onset of FND. This potential link was represented alongside the more common beliefs reported in the literature, with participants believing that vaccinations (14.3%), COVID-19 (10.8%) and viral infections (7.1%) could be potential aetiological factors. It has been reported that viruses can cause the body to generate an inflammatory response, and can lead to further physiological damage (Furman et al., 2019). However, caution is needed with these potential findings, as more research is needed to establish potential mechanisms of FND (Paredes-Echeverri et al., 2022).

5.4.2 Patient experiences of the clinical management of FND and beyond

One of the objectives of this study was to report the experiences of patients accessing services for their FND diagnosis and subsequent treatment. During the interviews, each patient was asked to discuss the support they had received (whether from family, friends, healthcare workers, the community or work for example) throughout their time accessing health services in order to receive their FND diagnosis and beyond. Patients focused largely on two aspects: the experiences of accessing health services and how FND had impacted all areas of their (and at times, their family's) life and livelihood.

The unpredictability of FND symptoms greatly affected patients, specifically how new symptoms, not experienced previously, would randomly occur. This in turn led to patients feeling isolated and grieving the loss of their independence, since they no longer felt safe to leave the house without support. They also missed out on many social functions, and at times, even 'everyday' appointments, as they were unable to have a haircut due to their tremor making it unsafe. The unpredictability of the severity of FND symptoms also negatively impacted patients vocationally, with the vast majority having to medically retire or leave their career much earlier than they wished which added financial stress to their living situation. From these details, it is perhaps not surprising that FND patients are likely to experience feelings of low mood, anxiety and poor quality of life (Carson and Lehn, 2016, Pick et al., 2019).

Learning to adapt to the new normal and their new FND label was an emotional discussion for many patient participants, particularly those who felt they were left to *“just get on with it”* [PT9]. Participants reported struggling to come to terms with the condition in the initial weeks and months after receiving the diagnosis, as well as feeling panicked and confused when being discharged from hospital. Difficulty in their understanding of FND (and the unpredictability of their FND symptoms) impacted on patients’ ability to adapt to the condition, with patients finding they were only able to adapt to their ‘new normal’ once they were able to recognise their symptoms, and subsequently prepare themselves for when their FND symptoms flared.

Patients perceived that healthcare workers were an integral part of the ‘village’ FND patients needed (when being supported during the clinical management of FND), particularly when receiving diagnostic information. Although some patients had positive experiences accessing health services and found healthcare workers supportive, others were left feeling confused or upset. Many patients reported a lack of communication when interacting with healthcare workers, leading to feelings of invalidation. This limited communication between healthcare workers and patients may be due to a lack of FND-training, leading to healthcare workers not feeling confident when giving the FND diagnosis. Patients experienced a change in attitude from healthcare workers, when it was believed they had another condition (such as epilepsy or stroke); this led to them being reluctant to report their FND diagnosis in future healthcare appointments, or even doubting their own symptoms. This may have an impact on the development of the patient-healthcare relationship, as patients may not feel able to trust the healthcare worker, due to their change in attitude or use of language. In contrast, patients who were shown empathy and compassion from healthcare workers were left feeling that they had ‘been heard’, and were able to trust and be vulnerable around the healthcare workers.

When receiving their diagnosis, patients were not readily signposted to charitable organisations or other healthcare-based services. While many patient and caregiver participants wished to be signposted, healthcare workers were reluctant to do this due to not being able to check the quality of information being provided by organisations or peer support groups. The lack of signposting highlights a need currently not being met by the NHS. It is worth considering that it may be difficult for some healthcare workers to signpost to relevant services, or create and manage a peer support group due to a lack of funding (or a lack of FND-appropriate healthcare in their geographic area or NHS Trust). It may be worthwhile for them to consider signposting patients to relevant organisations (such as FND Hope UK) who provide accurate information, which is both relevant and accessible for FND patients. Being left to explore other avenues for support, patients and caregivers utilised social media platforms for peer support and general information seeking. Interestingly, patients who had access to face-to-face peer support were much less receptive to attending the groups than patients accessing online peer support. This finding contrasts with previous research into the preferences of face-to-face and online peer support groups for other chronic conditions, who found that face-to-face support groups were better for information exchange and feelings of support (Huber et al., 2018). However, these differences could be due to the age of the participants in the current study, who were on average 20 years younger than those in Huber and colleagues (2018) research.

The experiences of accessing different treatment options (to alleviate FND symptoms) were a major discussion point. Participants perceived the attempt to access treatment options as a ‘road to nowhere’, where they faced numerous barriers when attempting to access services. The ‘postcode lottery’, where access to services is dependent on geographic location (Graley et al., 2011), caused severe accessibility issues and increased treatment burden for participants in this study. Due to a lack of appropriate services in their area, some patients were forced to travel to a different region to receive care. This was especially difficult for those who were unable to drive, having to rely instead on family members, or trust unpredictable public transport to take them to their appointment. Others found themselves having to wait more than two years on a waiting list in order to be assessed or treated by an appropriate service. Lastly, some patients found that as soon as they had received their FND diagnosis, they were unable to access support due to services not having suitable equipment (such as different sized mats in the paediatric physiotherapy service for children and adolescents of all ages and heights), or were passed from *“pillar to post”* [PT4] between services, who were unable to provide sufficient support. These are worrying findings, as it has been established that delays in treatment lead to poorer clinical outcomes (Gelauff and Stone, 2016). Some decided to take matters into their own hands by arranging their own treatment, implementing coping strategies or self-managing their symptoms. Participants discussed patients’ readiness for treatment, and how at times they avoided accessing healthcare.

5.4.3 Caregivers experiences of supporting FND patients

The impact of caregiving for patients with FND has not been widely researched. Caregivers in the current study were asked to describe their perspectives of providing support to a person (or people, in the case of one caregiver) with FND. Understandably, many of the caregivers were emotional when describing both the burden and pressure placed upon them, feeling that they were not allowed to discuss their *“frustration”* [CG2] and *“distress”* [CG5] with their family and friends, leading to them putting *“on this act…that everything’s fine”* [CG2]. The stigma of being unable to discuss their own struggles was especially felt by one caregiver, who was even told by a friend to stop communicating her worries about caregiving duties with her husband (the person she supports), as it could cause him stress and worsen his FND symptoms.

Caregivers provided a wide range of support, from providing emotional, financial and physical support, as well as advocating heavily for the person they support in clinical, work, and educational settings. Advocacy was seen as a crucial component of the caregiving role, as *“badgering”* [CG8] services and healthcare workers ensured patients were seen by clinical services in a timely manner. The role of caregivers in the clinical management of FND was reflected on by all participants. Although caregivers felt they should be involved in all stages (as they not only have intimate knowledge of the patient’s FND symptoms and how they are presenting), healthcare workers were reluctant; caregivers could inadvertently have a negative effect on care by disagreeing with potential treatment options, or talk over the patient. Caregivers of children and adolescents felt it was imperative for them to be involved, but acknowledged that the child should also be involved *“if they're obviously old enough to be part of it”* [CG7].

Caregivers had to learn to live with the FND diagnosis and the upheaval to the livelihood of the person they support as well as their own. Caregivers grieved for the loss of their pre-FND, caregiving life, and how they now had to prepare well, due to being unable to predict when FND symptoms would occur. Receiving support was a difficult conversation for some, as they felt that they were just doing their duties as a spouse or parent, and did not see themselves as an ‘official’ caregiver. Those who wished for support predominantly wished to be *“able to speak to somebody*” [CG2], with some seeing their interview participation as a way to speak to someone who understood the condition and also had experience of the caregiver role. Those who accessed support from charitable organisations expressed their gratitude for the support they received, whereas others accessed support from other caregivers, as they were able to “*offload in an environment which is non-critical, non-judgmental, where there's an understanding”* [CG3].

5.4.4 Healthcare workers FND-related attitudes and beliefs

All participants were asked to report on their experiences and perspectives of the FND-specific beliefs, and the attitudes expressed by healthcare workers. Unsurprisingly, views contrasted greatly between patient, caregiver and healthcare worker participants, with the first two groups reporting very negative experiences, whereas the healthcare workers provided great detail on how they believe in the condition and support patients in a variety of ways. This contrast may be due to the participants recruited to this study. Healthcare worker participants were very supportive of FND patients and associated caregivers, and worked incredibly hard to ensure that they received the support they needed in a timely manner. These attitudes differed from those reported in previous literature (Sahaya et al., 2012, O'Connell, 2017), which found that negative attitudes and stigma were prevalent in healthcare workers across a wide range of clinical settings and specialities.

Participants discussed a wide range of experiences around interacting with healthcare workers (or from the healthcare worker perspectives, hearing about these experiences and then relaying them during their interview). Although a small number of participants reported positive experiences when being supported in health services, most experienced negative attitudes and dismissive behaviour from healthcare workers. Healthcare workers not believing FND is a ‘real condition’, or that FND patients were *“malingering”* [CG5], led to patients being treated poorly. Patients experienced a change in attitude when it was first believed they had another condition (such as epilepsy or stroke), leading to them being reluctant to report their FND diagnosis in future healthcare appointments, or even doubting their own symptoms. Although many patients experienced dismissive and stigmatised attitudes from healthcare workers, some used these experiences as motivation “*to prove [the healthcare workers] wrong”* [PT1].

Negative attitudes and dismissive behaviour appeared to go hand in hand during the diagnostic process. Healthcare workers reflected that although they themselves displayed a *“good attitude”* [HCW2] towards the clinical management of FND and supported FND patients effectively, they were aware of *“flippant”* [HCW2] or *“old school”* [HCW3] attitudes that patients experienced from healthcare workers in other services. These old-school attitudes were prevalent in the experiences reported by patients, with one patient being told by a consultant doctor that FND is just a “*psychiatric condition seen in hysterical women”* [PT8].

Healthcare workers’ interest in the condition, and also supporting FND patients, was discussed at length. Patients reflected on how the healthcare worker they interacted with *“couldn’t be bothered”* but their peer was *“fascinated [and] wanted to know everything about it”* [CG4]. One patient reflected on how they were surprised at how little interest healthcare workers showed in their condition. This lack of interest, or willingness to engage with FND patients, may stem from a lack of awareness in the disorder. Although FND is the second most common reason for neurology appointments (Stone et al., 2010), the lack of awareness and understanding of FND was apparent from the reflections by both healthcare worker and patient participants.

Patients and caregivers reflected on how these negative experiences may be due to the beliefs of the healthcare workers who may not have received adequate, FND-specific training. At times, they felt they were learning about FND at the same time as the healthcare workers providing care for them (or for the person they support), reflecting that it was *"more like a mystery tour than the path of the recovery"* [CG1]. These views were supported by healthcare worker participants, who acknowledged how few healthcare workers had received training on FND, and were inexperienced in working with patients with the condition. While the healthcare worker participants were supportive of FND patients and wholly believed that FND is a real health condition, the difference in confidence levels between them as apparent. Those who were recently trained professionals (within the past five years) were more reluctant to signpost patients to organisations or highlight relevant information on websites, whereas senior healthcare workers (such as consultants) were confident in passing on information and referring patients to outside services.

Overall, participant views from all three population groups aligned. Patient and caregiver participants spoke at length on their thoughts of accessing UK health services for the clinical management of FND. Feelings of disillusion were prominent throughout their experiences, with participants becoming disappointed at how little support or communication they received from both healthcare workers and services. Indeed, patients faced stigma and at times, poor quality care when attempting to have their symptoms diagnosed and subsequently managed. While the perspectives and experiences shared by healthcare worker participants demonstrated how they themselves go above and beyond to provide suitable and person-centred care for their FND patients, they were aware that their behaviour and dedication was not shared by healthcare workers based in wider health services. Reflections on the reasons why healthcare workers may not be providing suitable care were shared by many participants, with the main perceptions being a lack of FND-specific education or knowledge leading to healthcare workers not understanding or being aware of the condition, or limited resources being a barrier to effective support. These experiences and perspectives indicate that the clinical management of FND in the UK needs to be improved to ensure patients are receiving high-quality, and timely, care. Implications of these findings, and ideas and recommendations on how to improve the clinical management of FND in UK services, are discussed in Sections 7.2 and 7.3.

5.4.5 Strengths and limitations

The majority of participants were purposively recruited to this study (n = 21), and also took part in the survey study (Chapter 4). This allowed for a diverse group of participants, with equally diverse views, to share their perspectives and experiences of the clinical management of FND. These diverse views benefitted this study, as it allowed for a more detailed, and rich telling of the clinical management of FND. To maintain confidentiality, demographic data collected were kept to a minimum, and geographic location was recorded at regional level. Although healthcare workers were asked to disclose their job title and service type, NHS Trust and department information was not disclosed, to allow healthcare worker participants the opportunity to provide their experiences of working with FND patients, whilst maintaining their confidentiality without concern.

Prospective participants were contacted three times over a one-month period, to give them sufficient time to decide whether they wished to take part in the study; once all willing participants were interviewed, recruitment ceased. In total, 28 participants were recruited to the study. This sample size ensured the data analysis was not limited or compromised by credibility or dependability issues (Lincoln and Guba, 1985). Although purposive sampling was used to recruit the majority of participants, recruiting the final healthcare worker participants was challenging. To overcome this challenge, a recruitment drive was pushed on social media (predominantly Twitter) and word of mouth.

Utilising a semi-structured approach allowed for flexibility during the interview process. The interviews were not strictly guided by the bespoke interview guides, which was useful as a wealth of relevant information was gathered via discussions with each participant, rather than relying on participants responding to fixed questions. The bespoke topic guides were developed from recently published evidence reported in the conducted scoping review (Chapter 2) and were discussed with patient and public involvement members.

Using a semi-structured interview approach enabled participants to feel at ease, as they were able to discuss topics important to them at a convenient time. Although it is best practice to conduct interviews face to face as it enables a rapport to be built between the interviewer and interviewee (Ritchie and Lewis, 2003), interviews were conducted over the phone or via Zoom, in line with the University’s COVID-19 guidance. To reduce the potential power imbalance between the interviewer and interviewee, the interviews were conducted with only the participant and interviewer present on the call or Zoom meeting. They took place in a suitable setting for the participant, where they were given opportunities to ask questions before, during and after the interview took place.

Although there are a number of strengths to this study, it is worth bearing in mind the limitations, especially the chance of selection bias. The views and experiences provided by healthcare worker participants may not be truly reflective of the wider population. While efforts were made to recruit healthcare workers located across the UK (and from different professions), not all geographic areas or professions were represented in the sample. The issue of selection bias is pertinent, especially when examining the patient and caregiver experiences provided throughout this study and the previous survey (Chapter 4). Patient and caregiver participants may have wanted to participate in this study as they wished to report their negative experiences when accessing health services, which may not be a true reflection of overall patient and caregiver experiences. Therefore, demand characteristics may have skewed the results. Although purposive sampling can be advantageous to ensure certain demographic characteristics are included in a study, it is a limitation as random sampling was not utilised. Therefore, there is a chance sampling bias may have occurred.

While a large amount of effort was put in place to minimise interviewer bias and response bias, they still may have occurred and skewed the results. The topic guides were structured to minimise the use of leading or loaded questions, however, as the interviews were semi-structured, these types of questions may still have been erroneously asked by the interviewer and may have influenced a participant’s response.

Attempts were made to separate the reflections and experiences of caregivers who supported their children, versus those who cared for their adult family member or spouse. As participants had to be aged 18 years or over to take part in this study, the experiences of child and adolescent FND patients were not directly explored from their own perspective. Regarding the sample, the healthcare worker group did not reflect the whole range of professionals who work with FND patients. While a variety of roles was represented in this study (e.g., physiotherapists, psychologists, neurologists), GP and A&E worker views were not. Although attempts were made to recruit patients who were currently undergoing diagnostic assessments, only patients who had received a diagnosis and were accessing (or attempting to access) treatment services took part in this research. Therefore, it is unknown if the experiences of those who were awaiting diagnosis are different to those who have been diagnosed.

Though gender and age groups were represented in the patient group, the age range for caregivers was limited, and only one male caregiver was recruited. This limitation is not surprising, as unpaid caregivers tend to be female (Sharma et al., 2016), yet it does mean that male caregiver experiences are under-represented in this study. Further to this, the ethnicity of participants across all three groups was not diverse. Therefore, the experiences reported by study participants may contrast with the wider population of healthcare workers, caregivers and patients either accessing or working in health services.

5.4.6 Implications for clinical practice

The findings from this study highlight the variability and accessibility of FND-specific diagnostic services and treatments across the UK. The timescales for appointments are widely variable depending on location, with patients located outside of the main UK FND services (based in London, Edinburgh, and Bristol) having to wait over two years for appointments, or needing to travel to other regions in order to receive adequate support from services. While these delays may be due to budget cuts in a time of austerity, it still poses a significant clinical challenge as FND patients who face delays to diagnosis and treatment are more likely to experience negative clinical outcomes and poorer quality of life (Gelauff and Stone, 2016).

This study highlights the lack of communication and information sharing that occurs between patients, caregivers and healthcare workers during the clinical management of FND. This led to feelings of confusion, bewilderment and worry from patients, due to information not being shared, or not shared clearly, and patients ‘falling in between the gaps’ when being referred from one service to another. Improving relationships and collaboration between healthcare workers and services is needed, in order to better support FND patients accessing services; this could encourage information sharing and knowledge exchange.

Worryingly, outdated attitudes to FND (such as it is only a condition seen in ‘hysterical women’ or it is not a ‘real’ condition) are still prevalent in services and in turn, impact on the likelihood of patients being able to access healthcare. Supporting the findings from Chapter 4, healthcare workers based in wider health services are likely to be unaware of FND and more likely to believe patients are malingering. Patients who experience negative attitudes from healthcare workers or services are less likely to accept their diagnosis and engage with services (Fouche et al., 2019, Rawlings et al., 2017). This study reveals a need for FND-specific training and education for healthcare workers so they can better understand the condition. This can provide them with accurate and up-to-date information, as well as aid the development of UK clinical guidelines in order to effectively clinically manage FND in the NHS.

Calls for the utilisation of an MDT approach were once again brought to the forefront by healthcare worker participants. Healthcare workers reflected on how FND care fell onto one dedicated professional within their service, leading to patients facing longer delays to their care when this healthcare worker needed to take long term leave. This highlights the need for a more concerted approach to the clinical management of FND across services, perhaps met by the utilisation of MDTs.

5.5 Conclusion

This study presents in-depth and rich accounts of the lived experience from three different perspectives, namely, patients and caregivers (when accessing diagnostic and treatment services for FND), and the beliefs and attitudes of healthcare workers involved in the clinical management of FND. Twenty-eight participants from across the UK completed the study, allowing the opportunity for a snapshot of the current clinical management of FND across NHS Trusts to be obtained and analysed.

A wide range of experiences was provided from all population groups. The potential aetiological factors for FND were reported, including physiological and psychological trauma, chronic stress, as well as other mechanistic and genetic factors (such as viral infections causing inflammation in the body).

Perspectives on the clinical management of FND in UK-based health services contrasted widely between population groups. Patient and caregiver participants reported many instances of negative attitudes, stigma and dismissive behaviour from healthcare workers; utilised social media and peer support as an outlet, much to the dismay of healthcare worker participants. The impact of FND on patients and their loved ones' lives was described, as well as how they each learned to adapt to their new normal and the FND ‘label’.

Participants reflected on the lack of FND training and expertise in clinical services. Patients discussed how an education package is needed for healthcare workers to better understand FND, and also to support patients after they have received their FND diagnosis. Research is needed to develop these documents to adequately train healthcare workers, which can help support FND patients in services.

5.6 Reflections

As reported in Section 3.2.3.4, reflexive thematic analysis (RTA) was used to analyse the interview data. After evaluating other analytic methods, I reasoned that RTA was the most appropriate method for multiple reasons, not limited to its flexibility when analysing multiple data sources from a range of perspectives (Braun and Clarke, 2021). I conducted the analysis using an inductive approach, as it allowed the data to determine the themes (Braun and Clarke, 2021) and develop the story of how FND is clinically managed within UK services, and how FND patients navigate and experience these services.

Before reflecting on the analytic process, I would like to discuss my reflections when conducting the interviews. Naively, I did not expect to be affected by the topics discussed; I found some of the interviews, especially those which focused on poor mental health and distress to be particularly difficult. I was startled at the guilt I felt after the interviews; the participants disclosed very personal and vulnerable experiences, with some becoming very emotional. While I gave participants ample opportunity to pause or end the interview, and also debriefed them after the end of their interview, I still had some niggling guilt at the back of my mind. To my surprise, some of these participants (particularly the caregiver group) divulged that they wished to use their interview as an opportunity to discuss their innermost thoughts and feelings to an outside person, who understood their experiences. I felt very conflicted at this disclosure; while humbled that these participants trusted me with their experiences, I also felt quite scared by the pressure it placed on me!

It is also prudent to discuss how my background may have affected the interview process and subsequent analysis. While making a concerted effort to not let my background influence the questions being asked or affect the flow of the interviews, there may have been times when this occurred. On occasion, I felt conflicted about whether to signpost patients and caregivers to support groups and forums, as I was not sure if would be appropriate, especially since I only caught a snapshot of their life and experiences, and I did not want to overstep. When this situation occurred, I kept in mind my own position as an interviewer and researcher (and ultimately, an ‘outsider’ to their situation), while being empathetic to their situation.

My knowledge on FND diagnostic and treatment issues may have also shaped the analysis. As well as completing the scoping review and survey, I spent two years attending FND workshops and conferences, speaking to patients and caregivers about their own experiences on the clinical management of FND, and shadowing clinicians before commencing this interview study. Therefore, before starting the interview process, I had an awareness of some of the issues in the clinical management of FND (such as the stigma associated with the condition, the limited diagnostic tools available, and the lack of awareness of FND in wider NHS services). When participants discussed the issues they faced when receiving their diagnosis (or in the case of healthcare workers, discussing the issues they were aware of in the clinical management of FND), I made sure not to let my own knowledge influence or bias the interviews by mentioning my own thoughts on these issues.

The process of analysing the data (and the subsequent write-up of this chapter) was an arduous yet remarkable affair. While I closely followed the six phases set out in Braun and Clarke's guidelines (2021), at times I found the analysis overwhelming due to the amount of data collected; over 285 pages of interview text (containing over 185,000 words) were analysed in total. Throughout all stages of the analysis, I kept a reflexive diary so I was able to reflect on how my own worldview may have affected the analysis, any potential barriers or challenges, and any thoughts on potential items of interest. My reflections of completing each phase are detailed below.

5.6.1 Phase 1 (data familiarisation)

I ensured I was fully immersed in the data throughout each stage of the study. I wrote the study protocol and analysis plan, developed the interview topic guides for each population group, conducted and transcribed each interview, then analysed the data from all 28 interviews. I feel that the data familiarisation process started when I was conducting and transcribing the interviews as it gave me a raw insight into the participants' perspectives and experiences. Listening to, and reading the transcripts again was a valuable way to re-familiarise myself with the collected data. It also allowed me to start to understand and reflect on the emotions and vulnerability of the participants, who had disclosed many personal thoughts and feelings when discussing their experiences. During the familiarisation process, I jotted down notes on each transcript, these notes included items of potential interest, potential ideas to explore during the coding phase, or my own reflections.

5.6.2 Phase 2 (coding the data)

After becoming thoroughly familiarised with the data, I coded each interview in date order. While coding, I engaged with the data from each interview twice, in order to minimise the likelihood of missing any relevant information. Each sentence was read thoroughly and inclusively, making sure that the data were given a high level of attention. All data (that appeared to be relevant or interesting to the analysis) were coded. Coding the data was a painstaking process due to the amount of data collected from the interviews. To make sure I did not become overwhelmed by the coding, I broke up the coding process over two weeks. This length of time allowed me to keep revisiting the data with a fresh mind, without feeling 'bogged down'.

During the first round of coding, coding was predominantly semantic (such as ‘feeling upset as they were dismissed by their doctor’) as the codes described the data as conveyed by the participant. During the second round of coding, some latent coding occurred, as I attempted to capture further meanings to the participants’ experiences (such as ‘unspoken familial bonds’). While I would have preferred to code each interview on paper (as I would be able to see my comments and reflections easily), using NVivo to code and generate the themes was more time effective and efficient.

5.6.3 Phase 3 (generating initial themes)

Once the coding was completed, I began to generate initial themes. Before I clustered similar codes together and organised them into initial themes using NVivo, I spent time reflecting on the data collected from each interview and reading through the entries in my reflexive journal to ensure the generated themes represented the experiences and perspectives provided by the participants. This was important to me, as the experiences and perspectives of those involved in the clinical management of FND (particularly patients and caregivers) have not been well documented. Therefore, I wanted to make sure I was truly reflecting the participants’ experiences. After reviewing the data from the interviews to identify potential themes or patterns, I created a thematic map on NVivo (Figure 10). This map helped me to further understand the initial themes (and related sub-themes) and potential links between them.

5.6.4 Phase 4 (reviewing and developing themes)

After generating the initial themes, I checked each theme against the whole dataset. I reviewed each theme twice; the first to review the coherence of each code in relation to the theme and sub-theme in which it was situated, and the second to assess whether it represented the dataset in relation to the central concept of the research. If an initial theme or sub-theme was deemed to be irrelevant or not coherent, it was removed. To help me decide the relevance of a theme, I updated the thematic map multiple times to further understand how each theme, and its sub-themes, were related.

5.6.5 Phase 5 (refining, defining, and naming themes)

Before finalising and naming the themes, I reflected on how the data in each theme would be presented. I wanted to make sure that each theme’s story, and the overall story, would be an accurate representation of the experiences described by the study’s participants. To do this, I developed a written description of each theme (Appendix 12) using the information contained in the thematic map, and checked it against the data within the theme. If the check deemed that a theme was not a true reflection, I refined it. The thematic map was a useful tool throughout phases 4 and 5, as it allowed me to check for overlap between the themes, and whether I needed to clarify differences between sub-themes.

Once each theme was refined, I created titles for each theme and sub-theme. While developing the titles, I closely read through the data relating to each theme/sub-theme in order to make sure the titles accurately reflected the data contained in each theme.

5.6.6 Phase 6 (producing the report)

Producing the ‘report’ (rather, this chapter) was an iterative process. While writing, I found myself further refining each theme by re-checking codes, which helped me to better describe and interpret the data. This refinement also assisted in deciding which order the themes would be presented in, as re-reading the data reminded me of the narrative of each theme and the overall work. Throughout the analysis and writing process, I became acutely aware of the differences in opinions and experiences between the three population groups. To ensure I was reporting a balanced account, I made sure (where possible) that all three groups were represented in each theme. While at times this led to some contradictory quotes and narrative, it provided a true reflection of their experiences.

Chapter 6: Interpretation of Stage 2 data

This chapter connects the findings from the studies conducted in Stage two. A mixed sequential explanatory research design was implemented for stage two, which involved conducting an online survey (Chapter 4) and 28 interviews (Chapter 5). Methodological triangulation was utilised alongside this research design to reduce the potential biases, while providing a more thorough and comprehensive understanding of the research topic at hand.

The methods utilised for this work can be found in Chapter 3.

6.1 Key finding 1: The paucity of FND-specific education & training for healthcare workers

Healthcare workers' FND specific education, knowledge and training featured heavily throughout the survey and interview studies. Patients and caregivers commented on the large amount of healthcare workers unaware of FND, or that these workers' knowledge and education and/or training was inadequate. Several patient participants focused on how the healthcare worker(s), who conducted the diagnostic test(s) or provided the diagnosis, were uninformed about FND. The healthcare worker participants' perspectives supported these patient and caregiver experiences, acknowledging the lack of FND-specific training, general inexperience of healthcare workers caring for FND patients, and even the understanding of FND as a health condition.

Patients and caregivers reflected on the limited knowledge of healthcare workers in wider healthcare services, with some suggesting there is a lack of willingness to learn about the condition. Others commented how it felt like they were learning about FND at the same time as the healthcare workers providing care for them (or for the person they support), reflecting that it was *"more like a mystery tour than the path of the recovery"* [CG1]. These comments led to participants concluding that if FND-specific education or training packages were to be developed, they should focus on training healthcare workers to truly understand that FND is a heterogeneous condition. In addition, participants recommended that a training package should also explain how a one-size-fits-all approach is not achievable within health services, since patients can present with very different symptoms and therefore need individualised care and support.

Patient and caregiver experiences and comments were in line with the answers provided by healthcare workers in the survey study. Healthcare workers were asked to describe how knowledgeable they were regarding FND, and how much FND-specific training they had received to date. As detailed in Section 4.3.6, most respondents stated that they had moderate FND knowledge and expertise (n = 15; 53.6%), whereas only six respondents stated they were very knowledgeable (21.4%). Interestingly, only two of the four respondents, who had been working with FND patients for more than 20 years, rated themselves as ‘very knowledgeable’, perhaps highlighting the lack of FND-specific training available for healthcare workers. Four healthcare workers stated that they had received no specific FND training or education (16%), while seven had received training during their medical degree/speciality training (28%) and nine stated self-directed learning (36%). When asked if they deemed the training they received as sufficient, only seven respondents (25%) replied positively.

Healthcare worker confidence and expertise were linked to many experiences and perspectives reported by participants, with feelings of confidence when supporting FND patients, as well as being sufficiently trained, going hand-in-hand throughout the two studies. Interestingly, one healthcare worker commented that it does not need to be a specialist who provides suitable support for FND patients, rather *“it's not rocket science, it's just good people skills and, and listening and understanding people and their behaviour”* [HCW9]. This perspective was highlighted by a patient participant, finding that she was unable to access care and support, as the consultant in charge of her healthcare was “*a little bit too arrogant to accept his limitations and think, ‘I don't know, I'm going to ask somebody’”* [PT9].

This lack of FND knowledge and training not only had a direct impact on patient referrals to diagnostic and treatment services, but also on knowledge and information being passed on to patients themselves. Patients stated that they were given very limited information on FND, and had to resort to independently researching the condition to have a better understanding. This may be detrimental to patients, as information available online is often unmonitored and potentially inaccurate (Kim et al., 2018). Therefore, these findings suggest that informative and accurate FND training is needed to increase healthcare workers' knowledge and confidence, when working with FND patients and their caregivers.

6.2 Key finding 2: The importance of communication in the clinical management of FND

A further key finding is the lack of communication between healthcare workers, patients, caregivers and different health services. As discussed throughout this thesis, clear and effective communication between healthcare workers is crucial to ensure that patients receive timely care. Healthcare worker perspectives on effective communication were mixed, with some perceiving that effective communication is in place between other professionals and services, whereas others agreed with the perspectives of caregiver and patient participants, stating that communication between healthcare workers and teams was limited. Some patient participants perceived that their care was impeded due to the lack of communication between healthcare workers; they became distressed when being repeatedly asked to describe the onset of their FND symptoms by healthcare workers, who did not subsequently update the patient's clinic notes to inform other staff members.

Effective communication between healthcare workers employed in different services led to patients being given medical appointments in a suitable time frame, as it allowed for healthcare workers to *"expedite appointments quickly"* [HCW8] and created opportunities for collaborations and "*reciprocal arrangements"* [HCW10] between services. This positive outcome was further enhanced by healthcare workers who also communicated effectively with patients; one patient was referred to a neurology clinic after making an impromptu comment to their GP. Participants also reflected on the breakdown of communication when patients were discharged from diagnostic services, leading to patients 'falling between the gaps' and not being able to access appropriate care, as diagnostic and treatment services and teams were not communicating with one another.

Healthcare worker and patient perspectives differed greatly, both in communication between themselves and how information relating to the condition was relayed. Numerous respondents in the survey study (Chapter 4) left comments detailing the experiences of communication breakdown between healthcare workers and patients. Healthcare workers provided accounts on how they make sure they communicate clearly when speaking to patients, noting that when patients have accessed their service previously, it may "*be one of the first times people have felt they've been given an explanation for their symptoms"* [HCW3]. Participants focused on how some healthcare workers communicated poorly with patients by not explaining the FND diagnosis clearly, or not leaving enough time to communicate effectively. This unclear communication between patients and healthcare workers led to patients feeling worthless, isolated and less likely to accept their FND diagnosis. These feelings and experiences were also shared by patients and caregivers throughout the interview study, who perceived that the information they received from healthcare workers was not clear or understandable, leading to confusion, bewilderment and anxiety.

Healthcare worker participants admitting to feeling *"responsible for [their] profession because these patients don't always get a good deal"* [HCW10] and aimed to validate their patients' emotions and symptoms. Although healthcare workers were aware that the FND diagnosis appointment is typically a "*difficult conversation"* [HCW7], patients were left feeling confused or upset due to the abrupt language, lack of information provided or the *"medical jargon"* [PT7] used in an attempt to communicate the diagnosis. This confusion from the lack of clear information on their diagnosis of FND and potential treatment options led to patients and caregivers searching for information, utilising "*Dr Google"* [PT4] and social media.

In addition to describing the impact of communication issues, participants commented on how communication breakdown could be improved by utilising a multidisciplinary team approach (MDT). Indeed, an integrated approach would support better communication practices, as healthcare workers would be working together; this would lead to fewer patients 'being lost in the system', as they would not need to access multiple services for the clinical management of FND. This idea was supported throughout the interviews, finding that healthcare workers employed in multidisciplinary teams were able to easily communicate with one another, therefore allowing them to readily support their patients. This finding is timely, as integrated care approaches are currently being implemented throughout NHS Trusts in England, in order to improve the quality of care and support offered to patients with complex conditions (NHS England and NHS Improvement, 2021).

Limited communication, or a breakdown in communication between healthcare workers and patients, may be due to a lack of ability to adapt to different situations. Effective communication is needed throughout the diagnosis and treatment of FND, so that a patient fully understands and accepts their diagnosis, and also realises the importance of treatment adherence to manage their FND symptoms.

6.3 Key finding 3: Availability of resources and the 'postcode lottery'

While diminishing resources can be linked to other health conditions and health services, a focus on the availability of resources for the clinical management of FND is still meaningful and worthwhile. This is due to the current lack of official FND clinical guidance in the UK, meaning that services across the UK could be diagnosing and supporting FND patients very differently. This may lead to a 'postcode lottery' for patients, where some are able to access a variety of support, while others are not. This notion was supported by the findings from the survey study (Chapter 4). The 'postcode lottery' negatively impacted patients, with some having to wait more than two years on a waiting list to be assessed or treated by an appropriate service. To combat this issue, patients admitted to deliberately accessing services in certain geographic areas where family or spouses lived, in order to *"have a better chance"* [PT9] of receiving treatment in good time.

Survey respondents focused on the lack of resources available, specifically the duration of appointments, healthcare worker availability and resources provided by services (such as physiotherapy equipment). It appears that many FND patients face lengthy waits to access services; 42% of patient respondents had to wait over one year (from first reporting their symptoms to diagnosis), with 16.3% of these patients having to wait over five years. Similar figures were reported when patients were waiting to access treatment services, with some being able to access services "*within a couple of weeks*" [CG5], whereas others were placed on a waiting list over two years long. Healthcare workers discussed the waiting times for their own services, ranging from 14 weeks to over 52 weeks. These figures go well beyond the reported pre-pandemic median waiting time of 8.4 weeks to access treatments (British Medical Association, 2023).

Some healthcare worker respondents commented on the limited contact time when seeing FND patients, as complex cases need more time than other patients. Furthermore, these respondents (in a small number of NHS Trusts) stated there are time restrictions for appointment duration in place. While it is unknown whether there are consequences if appointments run over time limits, these limits are of particular concern, as it has been reported that a delayed diagnosis leads to higher healthcare costs (Cuoco et al., 2023).

In addition to lengthy waiting times or a limited time to assess or support FND patients, clinical resources appear to be lacking in certain geographical areas. A number of patients commented that there is a severe lack of services available for them to access, with one Northern Irish participant stating they needed to travel to England so they could receive their FND diagnosis. This is supported by a number of healthcare worker respondents, who stated that they have no FND services in their area, they are unable to refer FND patients to relevant services, or that referrals for FND patients are nearly always declined by their service. These are worrying findings, as it has been established that delays in treatment lead to poorer clinical outcomes (O'Keeffe et al., 2021).

Issues with healthcare resources were not just caused by geography. Healthcare worker availability and training impacted on the likelihood of appointments being scheduled. A common discussion point, made throughout both the survey and interview studies, was how healthcare workers left services due to retirement or illness, leading to patients having appointments cancelled and not rescheduled due to staffing shortages. Others found that as soon as they were diagnosed with FND, they were unable to access the service currently supporting them, as the service did not specialise in managing FND symptoms, or their case was too complex for local services to manage. Lastly, some patients were affected by the quality of available equipment to manage their symptoms, being denied access, or being placed on waiting lists to be given walking sticks, hospital transport or wheelchairs to assist in their everyday life.

Lengthy waiting lists and not receiving an initial or follow-up appointment in a timely manner led to some patients and caregivers accessing private health care. Individuals who were able to access private healthcare reflected on being in a fortunate position to do so; unfortunately, some of those people still struggled to access services quickly due to facing difficulties with insurance companies.

Healthcare workers reflected on the barriers to accessing healthcare and resources, commenting on how MDTs can be a facilitator to improving access to care, as otherwise there is a "*gaping hole in [the] service"* [HCW1]. This perspective was supported by other participants, declaring that utilising an MDT approach *"seems to be the winner"* [HCW10] because FND patients need *"specialist services, specialist and multi professional people, specialist teams, people who have that experience or have that knowledge, the understanding. It needs to be one team"* [HCW8].

It appears that a lack of resources is a serious concern in certain geographical areas, and healthcare workers are not able to dedicate enough time to support FND patients. Given that FND patients are more likely to experience worse outcomes the longer their symptoms go untreated, it is imperative that this is rectified. However, this finding should be taken in caution due to the lack of geographic representation in the survey and interview studies.

6.4 Key finding 4: The importance of support on FND acceptance and outcomes

Survey and interview responses highlighted the importance of 'the village', where support from family, friends and the community, along with healthcare and charitable organisations, have a direct impact on the likelihood of a patient accepting their FND diagnosis and their prognosis.

Participants across both studies perceived that healthcare workers were an integral part of 'the village' that FND patients needed when being supported during the clinical management of FND. These points highlight the significance of healthcare workers building trust and rapport to develop the patient-healthcare worker relationship, as a strong patient-healthcare worker relationship improves the likelihood of the patient accepting their diagnosis and improving patient outcomes (Fouche et al., 2019, Rawlings et al., 2017). A small number of patients, who experienced empathy and compassion when accessing services, felt heard and were more willing to trust and be vulnerable around the healthcare workers. However, over half of the patient survey respondents felt that healthcare workers were not supportive, and patient interview participants were confused or upset after interacting with healthcare workers, due to their dismissive attitude. Patients' negative experiences of healthcare workers caused them to lose trust in healthcare workers and become reluctant to access services.

Patients attended support groups or accessed support from social media (such as FND groups on social media), charitable organisations, social services and health services, as well as from family or friends. Interestingly, when asked to describe the support they would like to receive, patients focused on: peer support groups; active medical or healthcare service support; having an experienced professional or specialist to conduct the diagnostic tests; and having the same healthcare worker reviewing the diagnostic tests. Continuity of care was considered to be a key support type, as a number of participants perceived being abandoned, isolated or unsupported by healthcare workers once they had received their FND diagnosis. While healthcare workers reported that their service supports FND patients (and also signposts to relevant organisations and information), patients in the survey and interview studies did not care to engage with what was offered, possibly due to the passive options available (such as leaflets).

Participants reflected on 'community' support, specifically how peer support enabled patients to feel a sense of belonging, as they were able to engage with others who understood their condition and symptoms. Online peer support allowed patients to discuss and compare their symptoms and treatment management (much to the chagrin of some healthcare workers, who worried that peer support may be detrimental, due to the chance of FND symptoms being triggered by unhelpful comments), leading to friendships developing amongst members. Friendships were seen as imperative when accessing services and in everyday life, as friends were able to advocate or provide advice when the patient experienced severe symptoms.

Although healthcare workers and wider community support were of great importance, patient participants received most of their support from their caregivers, family and loved ones. Similar to the support received from friends, caregivers advocated heavily in medical situations, while ensuring the person they were supporting was able to move around safely at home. Participants reflected that family members initially struggled with their diagnosis and associated FND symptoms, sometimes leading to relationship and family breakdowns. However, those who were supported by their family received not only medical support, but also emotional and childcare support, while they accessed services or were suffering from severe symptoms.

Lastly, vocational and school support were discussed by participants. Schools struggled to support FND patients due to worries of tremors and seizures causing injury or were dismissive towards their pupils with an FND diagnosis, and were unable to understand why timetable amendments or requiring access to mobility devices may be needed. These experiences differed widely from those accessing support in their workplace, who allowed the patient and their caregiver time away from work, or provided opportunities to access private healthcare.

This 'village' approach enabled patients to access a variety of support, while ensuring they did not feel isolated. While not being able to fully comprehend what was being discussed during their diagnostic appointment, patients who had access to peer or caregiver support had the opportunity to discuss their worries or confusion with someone who understood their symptoms, and could also relate to them. Understanding the outcome of the diagnostic appointment is vital for a patient to accept their diagnosis, help them come to terms with the disorder and learn how to adapt to their 'new normal'.

6.5 Key finding 5: The impact of caregiving

The impact of caregiving for patients with FND has not been widely documented in research. Caregiver participants in both the survey and interview studies spoke at great length about how their caregiving duties not only negatively impacted themselves, but also their family and friends. Both patients and caregivers found themselves having to adapt and learn to live with their diagnosis, grieving for their 'pre-FND lives. Caregivers were heavily impacted by these adaptations, finding themselves having to adjust their living situations. For example, they bought larger vehicles so the person they supported could be transported safely home in case their FND symptoms became severe. Caregivers became creative in their ways to minimise the impact of the unpredictability of FND symptom flare-ups, developing "*seizure first aid kits"* [CG7] and *"go-bags"* [CG4].

Many caregivers reported how their caregiving duties negatively impacted their physical and/or mental wellbeing. Caregiving duties, such as moving or lifting the person they support, led to physical injuries; one caregiver reporting they needed physiotherapy due to the extent of injuries sustained. Although caregivers tentatively discussed their mental wellbeing throughout the interview study, numerous caregivers across both studies reported that providing support negatively affected their mental wellbeing, with some commenting that they *"put on [an] act…that everything's fine"* [CG2] while acknowledging that not expressing their feelings is not a healthy long-term solution. Caregivers felt they were unable, or not allowed to share their feelings with their family and friends, as the person they support was struggling more than they were.

The caregiving role took over many participants' lives; caregivers provided a wide range of emotional, financial and physical support, as well as advocating heavily for the person they support in clinical, work and educational settings. Some caregivers were forced to live on benefits to provide sufficient caregiving support, with almost one third (32.4%) of caregivers reported to be providing over 50 hours of care per week. Many were also in employment alongside providing support, leading them to have limited time away from work and caregiving duties, and becoming exhausted. Exhaustion from supporting a person with FND was disclosed as a reason for why caregivers were unable to socialise with friends and loved ones, leaving them feeling isolated. Caregivers explained how they avoided talking about FND in order to preserve friendships, or that it was too difficult a condition to explain.

Understandably, caregiver participants were emotional when describing the burden and pressure placed upon them, with the majority stating that they felt stressed and overwhelmed while providing ongoing support. Many felt that they did not have sufficient time to look after themselves, and needed professional support to help the person they provide care for. Even considering the possibility of accessing support was a difficult concept for some caregivers, as they felt that they were just doing the duties expected of a spouse or parent, and did not see themselves as an ‘official’ caregiver. Those who wished for support wanted an opportunity to speak to someone, allowing them the opportunity to *“offload in an environment which is non-critical, non-judgmental”* [CG3].

These findings are concerning, as it demonstrates the immense burden placed on caregivers when supporting FND patients. The majority of informal caregivers are unable to access training on how to provide physical support and assistance to patients, leading them to become injured when trying to lift or move the person they care for when their symptoms are too severe for the patient to move independently, or if they are in a potentially dangerous situation (for example, when having a functional seizure in public). The lack of support being offered to, or accessed by caregivers, may also have a detrimental impact. Many caregivers are in an unfortunate position of becoming exhausted or experiencing burnout as a result of full-time caregiving duties, combined with employment and managing other family duties.

6.6 Key finding 6: Healthcare workers attitudes and beliefs towards FND

Unfortunately, FND patients face negative attitudes and stigma from healthcare workers, being told that they are malingerers, and that they need to stop ‘faking’ their symptoms as FND is not a ‘real’ condition (Dosanjh et al., 2021, Robson and Lian, 2017). All three population groups (who participated in the survey and interview studies) were asked to report their experiences and perspectives on healthcare workers FND-specific beliefs and attitudes. While healthcare worker participants were positive when talking about their own, and their co-workers' beliefs and attitudes towards FND, patient and caregiver participants reported many instances of negative attitudes, stigma and dismissive behaviour from healthcare workers. Caregiver participants focused on how healthcare workers implied that the person they support was malingering, and how support and care from healthcare workers notably decreased when an FND diagnosis was suspected. Patients who experienced a change in attitude, when it was first believed they had another condition (such as epilepsy or stroke), became reluctant to disclose their FND diagnosis in later healthcare appointments, and even started to doubt their own symptoms.

Although many responses were negative, a small number of patient and caregiver respondents commented on how healthcare workers were understanding and compassionate. Healthcare worker participants acknowledged how they were aware of "*flippant"* [HCW2] and *"old school"* [HCW3] attitudes held by other healthcare staff. These outdated beliefs and attitudes were prevalent in reported experiences, with one male patient being told by a consultant doctor that FND is just a "*psychiatric condition seen in hysterical women"* [PT8]. Many patients reported how they experienced negative attitudes and unprofessional behaviour from healthcare workers, and were frequently dismissed when trying to communicate. This behaviour is concerning, as negative attitudes and beliefs can have a detrimental impact on patients (McWhirter et al., 2011). Participants discussed in great detail how these negative beliefs and attitudes led to some FND patients contemplating, or even attempting, suicide.

Healthcare workers' (employed in wider health services) willingness to support FND patients, as well as those showing a genuine interest in the condition, were discussed at length by both survey and interview participants. Patients in both studies described how healthcare workers, employed in services they accessed for diagnostic assessments and treatment management, were perceived as being deeply uninterested when supporting FND patients, with only a minority shown to be *"fascinated [and] wanted to know everything about it"* [CG4].

Participants reflected on the possible reasons why some healthcare workers held negative attitudes and beliefs towards FND. Caregiver and patient participants surmised that these negative attitudes (and the lack of interest or willingness to engage with FND patients) may stem from a lack of FND awareness in wider services. Although FND is the second most common condition seen in neurology services (Stone et al., 2010), healthcare workers outside of neurology (such as in GP offices or in accident and emergency departments) may have had very limited experience in supporting FND patients or received little or no FND-specific training. This lack of adequate training was reflected in patient and caregiver comments, who perceived that at times, they and their healthcare workers seemed to be simultaneously learning about the condition. These views were supported by healthcare worker participants, who acknowledged how healthcare workers were inexperienced when working with FND patients.

Evidence suggests that there is a link between patients experiencing negative attitudes and stigma from healthcare workers, and the likelihood of accepting their FND diagnosis before subsequently engaging with treatment services (Fouche et al., 2019, Rawlings et al., 2017). These attitudes and beliefs can have a detrimental impact not only on patients, but also on services and health utilisation costs.

6.7 Raising awareness of FND

These key findings are connected by one concept – awareness. Both patient needs and service burden may be improved by raising awareness of FND. Throughout the interview study, patients, caregivers and healthcare workers alike commented on how awareness can be raised by the development and rollout of two tailored education packages: one for patients to explain in plain language about FND, treatments, and support they can access; the other for healthcare workers, where they can be informed of the condition and how it is typically clinically managed. After this idea was brought up independently by several participants, the author probed subsequent participants to explore what they feel should be included in a tailored education package. These ideas are presented below.

6.7.1 Patient-specific education package

In total, 14 comments were provided from interview participants, when prompted on what they felt should be included in a patient-specific education package. Patient participants wished for an education booklet to be given to them, after they had received their FND diagnosis, in order to further explain the condition and the next steps in its clinical management. While some participants thought it would be beneficial for only general FND information or reassuring information to be included, others preferred hypothetical scenarios or a frequently asked questions (FAQ) section, which would explain what could happen with their symptoms. Lastly, information on how to access social services support or available resources was considered important to include.

Figure 15 provides examples of the information requested for a patient-specific education booklet. As some of the comments were similar, they have been collated. The shape size is in relation to the frequency with which the specific information was requested.

Figure 15: Patient-specific education booklet information

General information

[Include information on] "h*ow it impacts everyday life, not just the seizures, but the fact that it impacts everyday life."* [CG7]

[Provide] "*a booklet that the patient can work their way through gradually, just to increase their knowledge and understanding of it."* [HCW6]

Provide reassuring information for patients

"Include a lot of reassurance that they are believed, and they are not going mad." [HCW10]

[Provide] *"case study types, and saying 'maybe this is the kind of thing that can happen', and that, you know, the fact that it can build."* [CG7]

[Include information on] "*what they need to know - 'am I going to relapse? Where am I going to be in a year?"* [HCW10]

A clear explanation of FND

[Provide information] "*that explains the diagnosis and what it means." [*HCW7]

[Include] *"Brain image scans/pictorial method to show people what's happening in their brain."* [HCW10]

Information on resources

[Explain] "*what's available to them, what resources there are…how to access support, how to make a social services referral."* [PT6]

6.7.2 Healthcare worker-specific education package information

Contrasting the patient booklet, participants focused on improving the communication and language skills of healthcare workers during patient appointments, as well as providing a background of the condition and its clinical management. Interestingly, comments wishing for interpersonal skills training (to increase listening skills and rapport building) mainly came from healthcare worker participants.

Figure 16 provides examples of the information requested to be included in a healthcare worker-specific education package. As some of the comments were similar, they have been collated. The shape size is in relation to the frequency with which the specific information was requested.

Figure 16: Healthcare worker-specific education package information

The background of FND and how it is managed clinically

[Provide] *"more training for the medical professionals just to make them aware if someone has these symptoms, go down this road and look at the other signs, if it doesn't look like something else it could possibly be this. Just more awareness so the patient is not passed from pillar to post."* [PT4]

[Provide] "*information about what causes it, which would take a lot because it's so heterogeneous. And then the basic principles of treatment…cognitive behavioural principles, grounding, breathing, scaffolding on how to identify triggers, metaphors on how to explain what FND is, and how that is different from other neurological conditions, but no less valid or real."* [HCW1]

[Training to] *"ensure that other healthcare workers are aware of treatments, and that they're not using more kind of techniques that they would use with people who don't have functional symptoms."* [HCW5]

"Support in identifying FND cases." [HCW10]

Communication and language use

[Training on] *"how to sensitively respond to someone who's showing those symptoms in regard to not being pejorative, and using acceptable language."* [HCW1]

[Provide] *"tips about communicating the diagnosis."* [HCW5]

Developing interpersonal skills

"Explaining that you need to listen to the patient…listen to what they're going through and not be judging, using correct terminology." [CG5]

"Training on rapport building." [HCW6]

Explaining the healthcare worker role in the clinical management of FND

[Explaining] "*the healthcare professional's role." [HCW7]*

"Reinforcing that a lot of [FND support] is about transferable skills, and how they would use those skills with this patient group rather than seeing it as something entirely separate and strange." [HCW3]

While the ideas for these education packages cannot be generalisable, as only a small sample of participants provided information for their development, the mock-ups may be a useful starting point for a future research study. This future study could aim to create two co-produced, comprehensive education booklets, one to support patients after receiving their FND diagnosis, and the other to raise healthcare worker awareness of FND and understand how it is clinically managed.

6.8 Chapter summary

This chapter has provided an insight into the key findings from stage two of this doctoral research study. While awareness of FND across healthcare services and healthcare workers has steadily increased, the findings from the survey and interview work highlight how negative attitudes, beliefs and stigma are still prominent throughout the clinical management of FND. These negative attitudes and beliefs may still exist in services, due to the scarcity of FND-specific training and education provided to healthcare workers. Even though the majority of healthcare workers, who participated in the survey or interview study, described themselves as knowledgeable or having FND expertise, many admitted that their training came from self-directed learning and that any training they had received was not sufficient.

As well as affecting the patient, FND has a negative impact on their family and loved ones. Caregivers tended to be a spouse or parent to the person needing support, juggling caregiving, vocational and family duties, while also learning to adapt to the intricacies of the FND diagnosis and unpredictability of symptoms. The impact of caregiving is important to document due to emotional burnout and pressure, as many caregivers felt they were unable to look after themselves while providing long-term, ongoing support.

This chapter highlights the complexity of the clinical management of FND, and how there are many variables involved in a patient both understanding and accepting their FND diagnosis, before subsequently adhering to treatments that manage their symptoms. Although many patients can access support from their community, healthcare settings or charitable organisations, severity of symptoms and clinical outcomes are still influenced by resource availability, as well as FND training and education. Patients who are unable to receive adequate healthcare and support from a confident and informed healthcare worker in a timely manner (due to the postcode lottery or lack of training) are likely to face poor clinical outcomes (O'Keeffe et al., 2021). Lastly, this chapter provides an example of potential education/training booklets for patients and healthcare workers.

Chapter 7: Discussion and conclusion

The aim of this thesis was to explore the clinical management of FND in the UK, and the lived experiences of those accessing or working in health services. This aim was met by the completion of three complementary research studies: a scoping review, which synthesised the current evidence on FND diagnostic and treatment tools; a survey, which investigated how FND is clinically managed across the UK; and an in-depth interview study, which explored the experiences and perspectives of those involved in, or accessing, UK health services for FND care and support.

This final chapter pulls together the overall findings from these three studies. The thesis's objectives are discussed in combination with the findings from each piece of research conducted. A discussion on the strengths and limitations of the overall thesis, as well as implications for clinical practice and recommendations for future research, are provided.

7.1 Overview of findings

As discussed throughout this thesis, there are knowledge gaps in how FND is clinically managed in the UK, and the experiences of how FND patients access UK services. This thesis attempted to address these knowledge gaps by answering the study objectives set out in the introduction chapter (Chapter 1). Before discussing the findings in relation to each objective, it is important to discuss cross-cutting themes. Cross-cutting themes, also known as horizontal themes, are issues or topics which intersect the research study and highlight how its findings can have a wider impact than originally anticipated (Cardiff University, 2020). While a standardised list of cross-cutting themes has not been developed, they do include topics such as gender equality, democracy or social exclusion.

The findings from this research highlight an important cross-cutting theme: health inequality. Health inequality refers to the unjust variability of an individual's (or societal group's) health status (The Kings Fund, 2020). Indicators of health inequality can include factors such as the individual's socioeconomic class, the quality of their housing or geographic location, or their ethnicity. As discussed in Chapter 4, patients in lower socioeconomic classes had significantly more FND symptoms than those in a higher socioeconomic class, were less likely to receive their FND diagnosis within one year of the condition's onset, and felt less supported when accessing health services.

Health inequalities not only focus on an individual's health, but also the opportunities they have in order to receive healthcare. Differences in access to private care (to circumvent health service waiting lists) were apparent between patients in different socioeconomic classes. While some patient participants were unhappy with their experiences of private healthcare, it did enable them to be able to access medical appointments which expedited their diagnosis and subsequent treatments.

This is a crucial finding. As highlighted throughout this thesis, delays in receiving an FND diagnosis or feelings of distrust in healthcare workers is linked to patients being reluctant to accept their FND diagnosis, and subsequently engage and adhere to treatment (Adams et al., 2018, Fouche et al., 2019, Rosebush and Mazurek, 2011), negatively impacting the patient's prognosis and quality of life.

7.1.1 Objective 1: Provide an overview of the literature related to the clinical management of FND, including: Identifying and summarising the different diagnostic methods used to diagnose a patient with FND and the treatments used to treat FND, and identify and compare international guidelines on the clinical management of FND

The scoping review's findings emphasised the variability in the approaches to the clinical management of FND. A large evidence base reporting the diagnostic tools and treatments used was found; it highlighted how this recent evidence (conducted over the past decade) has started to focus on utilising a positive, or 'rule-in' approach to confirm the FND diagnosis (such as positive clinical signs), compared to using diagnostic tools that 'rule-out' other neurological or organic health conditions. vEEG, fMRI and positive clinical signs were found to be the most accurate assessments when determining the FND diagnosis, which was done by reporting high levels of specificity and sensitivity. While it may not be surprising to discover diagnostic imaging tools are accurate in the detection of any abnormalities or organic disease, the high costs associated in the running of these assessments cannot be ignored. Funding for NHS health services did not increase in line with inflation between 2010 and 2020 (Merry and Gainsbury, 2023), meaning that there has been very limited funding to purchase expensive technology. Therefore, it is important that new diagnostic assessments are developed and evaluated for both clinical-and cost-effectiveness. With this in mind, the scoping review discovered that a new wave of diagnostic assessments, involving the detection of biomarkers and serum proteins in the blood, are currently underway, with early studies demonstrating their usefulness as potential predictors of FND. As blood tests are likely to be less costly to the NHS than diagnostic imaging techniques, future research may find that the new wave of diagnostic assessments are both clinically- and cost-effective.

Although psychotherapy has been recommended in other nations' clinical guidelines as the main treatment to manage and reduce FND symptoms, the treatment with the biggest evidence base was medication. The reported effectiveness of medication was mixed, with some (haloperidol) being much more effective in managing FND symptoms than others (sertraline). Psychotherapy evidence (included in the review) also reported mixed effectiveness; CBT, in conjunction with APA, was found to be more effective than CBT alone. Physiotherapy, psychoeducation and self-help websites were found to significantly improve psychological and/or physical symptoms.

Only three official sets of published FND clinical guidelines were retrieved during the scoping review work, all from European countries (Danish College of General Practitioners, 2013, GGZ Standaarden, 2021, Roenneberg et al., 2019). All three guidelines promote a multi-disciplinary and integrative, stepped care for the clinical management of FND, and emphasise the importance of the patient-healthcare worker relationship.

While each guideline was developed using evidence-based studies, only the Dutch and German guidelines (GGZ Standaarden, 2021, Roenneberg et al., 2019) were updated with recent research and recommendations. Therefore, the Danish guidelines may be utilising old and outdated information. Recently, an optimal clinical pathway for adults with FND has been published in the UK (National Neurosciences Advisory Group, 2023), bringing into focus good clinical practice for the clinical management of FND. However, at the time of writing, this document has not been established as an official guideline.

To conclude, the scoping review provided an in-depth overview of the current diagnostic methods and the treatments used in the clinical management of FND, as well as comparing international FND guidelines. Therefore, objective 1 was met. However, caution should be applied when considering the findings of this work. The majority of the synthesised evidence was retrieved from underpowered studies, where only a small number of participants were recruited; the studies did not use a randomised controlled trial design (which are considered the ‘gold standard’ research design; Hariton and Locascio, 2018). This indicated that more rigorous studies are needed to test the effectiveness of the diagnostic assessments and treatments used to clinically manage FND.

7.1.2 Objective 2: Identify the tools and instruments used during the FND diagnostic process and treatments and interventions used to support a patient with FND in the UK

The scoping review reported the different diagnostic tools and treatments available in the clinical management of FND. At the time of writing, no study has reported which tools and treatments are used in the UK. Survey findings and Freedom of Information (FOI) requests were used to collate this information, with diagnostic tool and intervention data reported by 309 participants located in 22 UK regions, and 24 FOI requests from NHS

Trusts across the UK. The main diagnostic tests (reported across all regions) were neurological exams, blood tests, positive clinical signs and EEGs. The most common treatment interventions were physiotherapy, medication, CBT and occupational therapy. These results are mostly consistent with the findings reported in the scoping review. This confirms that services are seeking out and following up-to-date, evidence-based research, despite not having a UK clinical guideline to inform them on the best practice when delivering high-quality FND care.

Geographic location played a large part in determining the types of assessments and treatments used in the clinical management of FND. Survey respondents based in England reported that MRI scans were the most commonly used assessment to assist in their FND diagnosis, whereas survey respondents located in Wales or Scotland reported that services were equally as likely to use blood tests or MRI scans as the main diagnostic tool. Regarding treatment options, patients in England were more likely to receive physiotherapy, whereas patients in Scotland and Wales were more likely to be prescribed medication or receive CBT.

Healthcare worker respondents were asked how FND should be clinically managed by health services. Neurological exams (including imaging scans), MRI scans, EEG tests, positive clinical signs and psychiatric assessments were deemed to be the most necessary assessment to diagnose FND, indicating that a holistic approach to FND diagnosis is needed. Occupational therapy, psychoeducation, physiotherapy and psychotherapy (including CBT) were considered the most appropriate treatment options to manage FND symptoms. Interestingly, healthcare worker respondents stated that all treatments (except medication) should be offered by services, yet many patients were still prescribed medication to manage their FND symptoms. This is concerning, as it highlights that healthcare workers (who are uninformed of FND and the research surrounding its clinical management) are unaware that psychological treatments should be offered, rather than prescribing medication to manage FND symptoms (Danish College of General Practitioners, 2013, GGZ Standaarden, 2021).

Findings on whether healthcare workers perceived the FND treatments (offered by their service) to be effective was concerning. Only 68.3% of respondents (who were involved in FND treatment processes) answering the question stated they were effective; those answering negatively stated how a lack of time, service availability or healthcare worker training affected the quality of treatments offered by their service. This unfortunate finding showcases the limited resources NHS Trusts currently have, indicating that training for healthcare workers needs to be implemented as well as further monetary resources which may improve service availability (as well as reduce staff workload).

This objective has been partially met. The survey study identified the tools and instruments used in the clinical management of FND across the UK, however the survey sample was too small to state that these findings are truly representative. Due to time and budget constraints, it was not possible to access and use large healthcare databases (such as the Clinical Practice Research Database [CPRD] or the Hospital Episode Statistics [HES] database) to accurately determine the FND diagnostic and treatment tools used in each service. While a freedom of information request was sent to NHS Trusts across the UK to try to ascertain this information, the received responses were sparse (with some Trusts reporting that they did not record any FND clinical management information).

7.1.3 Objective 3: Identify patient needs during the diagnostic and treatment process for FND

Patient needs were identified in all three studies conducted as part of this doctoral research. Patients perceived that healthcare workers were integral to the support they needed during the clinical management of FND, particularly when receiving diagnostic information. Similarly, support from family members, friends, and even the workplace were reported as being great resources in supporting patients and helping them cope throughout the FND diagnostic process. While wanting continuity of care, patients reflected on how their experiences of healthcare services had led them to lose trust and, for some, subsequently refuse to access services in the future. This highlights the importance of healthcare workers regaining and building trust and rapport, in order to develop a strong patient-healthcare worker relationship.

Having access to a group or network of patients and caregivers who have FND (or understand FND) was seen as vital for many patients. Although health services offered passive support to patients (such as providing information leaflets or signposting to charitable organisations), being able to make connections with others who understand their perspectives and experiences was preferred by patients. The development of social media platforms and online peer support groups allowed patients and caregivers to connect globally, share their experiences, and provide support and advice.

Open and clear communication was identified as a basic need; patients without this were left feeling invalidated, bewildered or upset, due to limited or confusing communication with healthcare workers when receiving their FND diagnosis. Difficulty in understanding their FND diagnosis impacted on patients’ ability to adapt to the disorder, with patients finding they were only able to adapt to their ‘new normal’ once they were able to recognise their symptoms, and later prepare themselves for when their FND symptoms flared.

Compassion and empathy from healthcare workers were also identified as patient needs. Negative attitudes and dismissive behaviour from healthcare workers (when undergoing diagnostic tests and treatment) were reported by the majority of patient and caregiver participants, leading to patients rejecting their diagnosis and doubting their symptoms were ‘real’, or even suffering from mental health issues, leading to some patients attempting suicide.

Having access to appointments and medical equipment in a timely manner was identified as imperative by patients. However, experiences reported in both the survey and interview studies showed the limitations of services to provide suitable support for FND patients. Participants perceived the attempt to access treatment options as a ‘road to nowhere’, where they faced numerous barriers (including lengthy waiting lists or a postcode lottery) when attempting to access services. Others found that as soon as they had received their FND service, they were unable to access support. Services often had no necessary equipment available, or patients found themselves being passed from ‘pillar to post’ between services, who were unable to treat them.

The findings from the survey study presented a wealth of information on patient needs, which helped to inform the topic guides used in the interview study. Participants described how the clinical management of FND could be better tailored to meet patient needs, by focusing on improved communication between healthcare workers and the patient (and also between health services), patient-healthcare worker relationships, and also stronger support options. Therefore, it can be concluded that this objective has been met.

7.1.4 Objective 4: Explore the experiences of healthcare workers, patients, and caregivers on the diagnostic and treatment processes for FND, including: understanding the experiences of caregivers providing support to people with FND and understanding the attitudes and beliefs of healthcare workers working with patients diagnosed with FND

The findings from each study, conducted as part of this doctoral research, emphasised how FND impacts everyone involved in the clinical management of FND, and how the limitations of services and healthcare workers impacted on patients’ mental health and clinical outcomes. While findings demonstrated that healthcare worker participants' attitudes were positive towards FND, negative attitudes, stigma and dismissive behaviour from healthcare workers outside of this research were prominent when accessing diagnostic and treatment services. Accusations of malingering were frequent in hospital settings, as well as diminishing support and care from healthcare workers when the FND diagnosis was suspected. Although many responses were negative, a small number of patient and caregiver respondents commented on how healthcare workers were supportive.

The evidence provided throughout all three studies emphasised healthcare workers' interest in the condition and working with FND patients. The findings indicate that many healthcare workers employed outside of FND-specific teams or services were not interested in FND or supporting FND patients, and only a minority were fascinated, as they were previously unaware of the condition and wished to be informed. However, it is difficult to pinpoint the exact reason for this lack of interest, and whether it relates directly to FND as a health condition. For example, healthcare workers employed in a large hospital with a large caseload may not have the time or the resources to research or learn about a condition they were previously unaware of.

The survey and interview findings highlighted that poor communication contributed to the breakdown of patient-healthcare worker relationships and shared decision-making. Patients often left diagnostic appointments bewildered, upset and distrustful of healthcare workers, due to the limited information shared by healthcare workers. This indicated a lack of understanding of FND, or perhaps a lack of confidence from the healthcare workers when explaining the FND diagnosis. Patients were ill-informed of their diagnosis and were not informed of the most appropriate treatment options to manage their FND symptoms, finding that the treatment decisions were generally *"out of their hands"* [PT1086]. With many patients not being aware of why they were referred to their service, healthcare worker participants often found themselves spending the first scheduled appointment with patients educating them on FND. They had to explain how their service can manage their symptoms, while simultaneously attempting to gain the patient's trust to ensure they adhered to their treatment.

Waiting lists and limited health resources led to many patients being unable to access diagnostic and treatment services, with some finding they 'fell through the cracks' and were never offered an appointment, due to being placed on waiting lists over two years long. Reciprocal relationships were set up between some healthcare workers and services to lessen resource burden, and in turn, improve patient outcomes. Multidisciplinary teams (MDT) were often cited as a 'fantastic' way to support FND patients, ensuring they are able to access suitable support, without the need for referrals to outside services. MDTs would also reduce the risk of patients being lost in the system, or being supported by healthcare workers who were unaware of the condition.

Findings from this research demonstrate how informal caregivers are burdened not only by their caregiving duties, but also by health services. Caregivers were heavily involved in the clinical management of FND, finding themselves advocating for the person they support when they were unable to communicate, or explain their symptoms to healthcare workers. In addition, caregivers stepped in to provide care when healthcare workers were unable. Participants learned how to adapt to their new caregiving situation, and were creative in their ways to minimise the impact of unpredictable FND symptom flare-ups, developing *"seizure first aid kits"* [CG7] and *"go-bags"* [CG4].

Caregiving had a detrimental impact, leading to caregivers being forced to live on benefits in order to provide the level of support needed. Many were also in employment alongside providing support, yet almost one third (32.4%) of caregivers reported providing over 50 hours of care per week. Caregivers found that their dreams were put on hold, with some needing to quit their job or stay in employment for longer than planned, so they could provide care and financial support. Although caregivers suffered from both physical and mental health issues due to their caring duties, they perceived they were unable, or not allowed to share their worries or concerns with their family and friends, as they felt the person they support was struggling more than they were.

It can be deemed that this objective has been met. The findings from all three research studies have explored the experiences of healthcare workers, caregivers and patients on the clinical management of FND, using a variety of methods. The rich yet vulnerable experiences and perspectives collected as part of this thesis showcase the complexity of navigating and working in healthcare settings for FND care, and describe how FND can have a negative impact on healthcare workers and caregivers, as well as patients.

7.1.5 Objective 5: Document the potential triggers for the onset of FND

The aetiology of FND has been widely theorised throughout the ages. However, there is limited evidence regarding patient beliefs and perspectives on the reasons for the onset of FND. The findings from this thesis highlight the complexity of establishing the exact aetiology of FND, as a multitude of potential triggers were reported by participants. Chronic pain (41.2%), stress (40%) and mental health conditions (36.8%) were the most reported potential triggers for FND symptom onset in the survey study. These potential triggers were also supported by interview study participants. Participants tended to link more than one potential trigger to the onset of FND, with 91.2% of participants reporting more than one trigger, and 30.8% reporting five or more potential triggers. Interestingly, 14% of participants reported all three main potential triggers (stress, chronic pain and mental health conditions).

It is worth noting that there is a growing body of research which focuses on the potential link between the immune system and inflammation response being a potential FND trigger. This potential link was represented, with participants believing that vaccination responses, COVID-19 and viral infections could be potential aetiological factors.

This objective has been provisionally met. It was originally planned that the author would collect blood samples from patients, in order to study potential biological triggers for FND. However, due to constraints put in place by the University of York following the global COVID-19 pandemic, this work was unable to be completed. To adapt to this constraint, questions were incorporated into the survey and interviews to investigate participant perspectives on the triggers for FND onset. While the findings presented in this thesis around FND onset may not be generalisable, they do highlight patient perspectives on the reasons for why they felt they developed FND.

7.2 Strengths and limitations

Each individual study conducted as part of this doctoral research had a number of strengths and limitations. While each individual strength and limitation has been discussed within its respective chapter (presented in Sections 2.7.5, 4.5.5 and 5.4.5), the overall strengths and limitations of the research is provided below.

7.2.1 Thesis strengths

While the strengths of each individual study conducted as part of this thesis has been discussed in their own relevant chapter (presented in Sections 2.7.5, 4.5.5 and 5.4.5), it would be prudent to also review them as a collective. This thesis provides an important overview of recent diagnostic and treatment tools, together with a detailed insight from patient and caregiver perspectives on the clinical management of FND. The research utilised a mixed-methods study approach, which allowed for a thorough investigation into both the clinical management and the experiences of the clinical management of FND in UK health services. Each individual study was conducted sequentially, in order for the findings from each study to feed into the next. For example, the findings from the scoping review (Chapter 2) informed questions asked in the survey study (Chapter 4), which in turn informed the topic guides used in the interview study (Chapter 5). This structure ensured that each study element was informed by up-to-date and relevant evidence.

A substantial effort was made to ensure a range of views, from healthcare workers working across a variety of health settings and also patients based across the UK, were included in the survey and interview studies. This wide range of views, collected using a variety of research methods and analysed using a number of different techniques, provided a higher understanding of the core issues faced by those working or accessing diagnostic and treatment services. In addition, including participants from multiple population groups (patients, caregivers and healthcare workers) benefitted the research, as it allowed for an integration of experiences and perspectives from all aspects of the clinical management of FND in the UK, which may have been missed if only one population group was included. Patient and public involvement (PPI) representatives were involved during each stage of the research, which was of great importance to the author. PPI representatives were invited to provide relevant information for the scoping review via the consultation exercise, and were also involved in the development and subsequent amendments of the surveys and topic guides, checking the findings for accuracy and dissemination of the study results. Including PPI in research is incredibly important; PPI representatives are aware of issues that relate to accessing specific services, or living with a health condition that someone with indirect experience may not consider (NIHR, 2021). Therefore, they are able to provide an alternative perspective.

As highlighted in the scoping review (Chapter 2), there is a paucity of research exploring the lived experience of UK-based FND patients and caregivers. This doctoral thesis has begun to address this scarcity, and has provided valuable evidence on the impact of FND not only with patients, but also on their caregivers and family members. Though the survey and interview studies only recruited a small number of caregiver participants, the findings from both studies are still important and will be invaluable when informing future research.

The scoping review used a rigorous and systematic approach to gather evidence that answers its research aims and objectives. Multiple databases were searched using a search strategy (which was quality checked by a senior information specialist based in the Centre for Reviews and Dissemination), and a consultation exercise (involving contacting patients, caregivers and professionals involved in the clinical management of FND) was conducted. This was to reduce the likelihood of any biases relating to study identification and retrieve both internationally peer-reviewed and grey literature. Although not all foreign language papers were able to be included (due to financial and time constraints), where possible, studies published in other languages were assessed and included (if applicable).

Multiple reviewers reviewed each record at both selection stages (title and abstract, then full record), using a clear set of inclusion and exclusion criteria to reduce the chance of selection bias. Following guidance set by McHugh and colleagues (2012), inter-rater reliability was assessed using Cohen’s Kappa (Cohen, 1960).

Survey study recruitment well surpassed the projected sample size for patient participants, and was geographically representative and also representative of reported FND symptoms. Although recruitment occurred online due to limitations imposed by the COVID-19 pandemic, the recruitment strategy was inclusive and accessible. Purposive sampling was used to recruit for the interview study, allowing for a diverse group of participants, with equally diverse views, to share their perspectives and experiences of the clinical management of FND. These diverse views benefitted the interview study, as it allowed for a more detailed and richer telling of the clinical management of FND within the UK.

7.2.2 Thesis limitations

While there are a number of strengths to this work, it is worth bearing in mind the limitations. The majority of this thesis was completed during the COVID-19 pandemic, which caused considerable delays and led to adaptations to the research. For example, it was originally planned that an independent second reviewer would be involved in the data charting process for the scoping review; however, due to constraints caused by the COVID-19 pandemic lockdowns, only the main author was able to conduct this process. To limit potential bias, the data charting form used in the scoping review was piloted (20 records were charted and then assessed by the supervisors for any inconsistencies or inaccuracies), and the academic supervisors monitored and checked the process of the charting regularly (during the monthly PhD supervision meetings). The delays and adaptations caused by the pandemic have been described in the COVID-19 impact statement, which has been submitted alongside this thesis.

One limitation of this thesis is the timing of the scoping review. Whilst there is a limited amount of relevant literature within this field which focuses on UK perspectives and official clinical guidelines, recent contributions to this field have since been published after the review was conducted. For example, an optimal clinical pathway for FND was published in early 2023 (National Neurosciences Advisory Group, 2023). While an attempt has been made to include these recent publications throughout the rest of the thesis, it must be acknowledged that this information was not included in the review, therefore it did not help to shape the rest of the doctoral work.

While systematic reviews are seen as the ‘gold standard’ review type (Liberati et al., 2009, Smith and Noble, 2016), conducting a scoping review was deemed to be a more appropriate approach for this work, as it aimed to identify and map the current literature of a particular field, identify knowledge gaps and clarify key concepts (Munn et al., 2018). To ensure key, relevant literature was retrieved, the scoping review was conducted systematically and followed Arksey and O'Malley's (2005) guidance. Typically, a formal quality assessment is not completed when conducting a scoping review, therefore, the potential risk of bias in the included records has not been formally determined. However, the quality of included articles was judged according to the levels of evidence hierarchy set out by Glover and colleagues (2006; for more details see Section 2.4), which strengthened the findings of the overall research.

Stage two of the research had several limitations, particularly around recruitment. Participants were predominantly recruited via opportunistic sampling; therefore, were not fully representative of the FND patient, caregiver and healthcare worker communities. The attitudes and beliefs of the healthcare worker participants taking part may not be truly reflective of the healthcare staff working in wider health services. This is especially pertinent when examining the patient and caregiver experiences provided throughout this work, who had predominantly negative experiences when accessing health services. This is also a weakness of the patient and caregiver participants, who may have wanted to provide their experiences due to their negative nature, and may not have reflected the views of the wider patient and caregiver populations. Due to COVID-19 restrictions, study recruitment took place online. However, a range of patient and caregiver support groups and organisations were contacted to share the study; healthcare worker groups and organisations were also contacted to promote recruitment.

The transferability of the findings (reported throughout this study) may be questionable, due to FND patients being such a heterogeneous and exceptional population group. However, the findings are relevant not only to other patients with medically unexplained symptoms (such as chronic fatigue syndrome and fibromyalgia), but also to the inequalities of accessing healthcare within the UK.

Regarding the sample, the healthcare worker group did not reflect the whole range of medical staff who work with FND patients. While a variety of roles were represented (e.g., physiotherapists, psychologists, neurologists), GP and A&E worker views were not readily represented in the research findings. However, this criticism is quite typical of this area of research. Though some FND research studies involving healthcare workers did recruit GP workers and A&E workers, the predominant health professions that were recruited to studies were neurologists, nurses, as well as psychiatrists or psychologists (Begley et al., 2023, Lehn et al., 2019).

Though gender and age groups were represented well in the patient and healthcare worker population groups, the caregiver participants were predominantly female, aged between 45 and 54 years old. While this limitation is not surprising, as unpaid caregivers tend to be female (Office for National Statistics, 2023), it highlights that male caregiver experiences are underrepresented in this research. Even though the interview study had a similar number of caregivers, patients and healthcare workers participate, the survey sample size skews towards patient participants. A great deal of effort was put into recruiting healthcare workers and caregivers, however both groups narrowly missed the recruitment target (n = 28 and n = 34, respectively).

Lastly, the service mapping conducted as part of this research could have been strengthened via data linkage. Data linkage was originally considered and drafted into the plans for the survey study, and would have utilised the Clinical Practice Research Database (CPRD) and the Hospital Episode Statistics (HES) databases. However, due to the high costs associated with accessing these databases, alongside the lengthy waiting times it takes to access these datasets (once permission has been sought), it was determined that data linkage was not feasible in this research. In light of this, freedom of information requests were sent to NHS Trusts across the UK, in order to strengthen the service mapping.

7.3 Study implications

This thesis confirms that functional neurological disorder is a heterogeneous condition, which at times can be incredibly difficult to manage compared to other disorders. While awareness of FND within services is starting to increase, this thesis’s findings support previous evidence that there is a serious lack of FND-specific knowledge in health services (Klinke et al., 2019, Yu et al., 2023); this may have dire consequences for FND patients. FND-specific education and training is severely limited across all healthcare domains, with many healthcare workers only becoming knowledgeable about FND through self-directed learning. Healthcare workers in both the survey and interview studies reflected on the FND training they had received to date, with only a minority finding it was sufficient to support patients. It is evident that healthcare workers should be sufficiently trained on how to understand the complexity of FND symptoms, as well as diagnose and manage the condition. A small number of training courses, specifically designed for healthcare workers, have been provided by organisations (such as the Functional Neurological Disorder Society and FND Hope UK). Unfortunately, at the time of writing, there is no data available on the uptake of these courses via healthcare workers. The findings from this research also showcase the lack of FND-specific training or education implemented into formal education. It is imperative that FND-specific training and education sessions are implemented into university degree courses and other affiliated schemes (such as physiotherapy or occupational therapy training), in order to ensure healthcare workers are aware and have a better understanding of how to clinically manage FND.

The lack of FND-related knowledge and FND-specific training is concerning, and could be a major factor of the stigma and negative attitudes surrounding the condition. It has been previously suggested that providing education to healthcare workers reduces negative attitudes towards FND (McWhirter et al., 2011, Monzoni et al., 2011), yet to date this issue still has not been addressed. As discussed in the interview study (Chapter5), formal education focused around FND is not routinely delivered during medical training, and healthcare workers are having to actively seek FND-specific training. Therefore, the implementation of FND-specific education is needed, preferably during a healthcare worker's initial training (e.g., while completing their university degree), so they develop an awareness and understanding of the condition as early as possible.

Continuing these thoughts on FND-specific training, there is a possibility that the lack of official FND care guidelines in the UK is one reason why this training has not yet been implemented (into UK education institutions or health services). A lack of guidelines may indicate that FND is not a serious condition (to training course providers), and therefore does not need to be taught. This may lead course providers to feel unsure, or lack confidence on how to discuss its clinical management. FND is included in the suspected neurological conditions quality standard (National Institute for Health and Care Excellence [NICE], 2021), however the information contained in the standard relating to the disorder is scant at best. At the time of writing, there are no NICE clinical guidelines for the clinical management of FND, which is alarming. Healthcare workers may be unsure of where to find accurate information on the condition, or else they may not believe the condition exists due to the lack of official guidance. This is evident throughout this thesis; healthcare workers based in wider health services were reported as more likely to be unaware of FND and have outdated attitudes regarding FND (such as it being only a condition seen in 'hysterical women', it is not a 'real' condition, or patients were malingering), which in turn caused a negative impact on the likelihood of patients being able to access healthcare. These outdated attitudes were reported by all three population groups, with interview participants discussing in detail the stigma experienced in healthcare settings. Further clinical guidance from other European countries recommend psychological therapy instead of prescribing medication to manage FND symptoms (Danish College of General Practitioners, 2013, GGZ Standaarden, 2021, Roenneberg et al., 2019). However, prescribed medication was reported as one of the main treatment options offered to UK patients in the survey study (reported in Chapter 4). This thesis makes a valuable contribution by calling for the creation of future clinical guidelines. It is imperative that UK clinical guidelines are developed. Clinical guidelines support healthcare workers, as they use high-quality evidence to develop and provide an optimised care pathway, and will also ensure healthcare workers (employed in NHS Trusts across the UK) are offering similar standards of care and services for FND patients.

This thesis highlights the inequalities and variability of resources and care faced by patients. Timescales for appointments differ widely between services and are dependent on location; patients located outside of the main FND services (based in London, Edinburgh, and Bristol) had to wait over two years at times for appointments or needed to travel to other regions in order to receive adequate healthcare. This is perhaps not surprising as the main FND services are more likely to have access to FND-specific tools and assessments than other locations. Indeed, patient interview participants living outside of these areas struggled to receive suitable support during their diagnosis and treatment, leading to some self-managing their symptoms. While it is worth bearing in mind that these delays may be due to limited resources and budget cuts due to austerity, it still poses a clinical challenge, as FND patients who face delays in diagnosis and treatment are more likely to experience negative clinical outcomes (O'Keeffe et al., 2021). Therefore, attention is needed on the development of clinical guidelines and the inequalities of FND specific healthcare, to ensure patients are being clinically managed appropriately and in a timely manner.

The findings from this thesis indicate the importance of effective communication between services, and also between healthcare workers and patients. While training and education is essential to improve patient experiences when accessing clinical services for the management of FND, services and healthcare workers need to recognise the impact of their communication skills on patient acceptance and adherence to treatment. Findings from the interview study emphasised the lack of communication and information sharing that occurs between patients, caregivers and healthcare workers during the clinical management of FND; it also highlights the impact on the patient-healthcare worker relationship. Patients were left with feelings of confusion, bewilderment and worry due to information not being shared, or not shared clearly. Improving relationships and collaboration between healthcare workers and services is needed, in order to better support FND patients accessing services, and encourage information sharing and knowledge exchange. A push towards developing multidisciplinary teams (MDTs) is needed to reduce waiting times and breakdowns in communication, and also allow for the patient-healthcare worker to develop. As discussed by healthcare workers who participated in the interview study, MDTs were deemed as a major facilitator towards good patient care in the management of FND. Participants reflected on how FND care fell onto one dedicated professional within their service, leading to patients facing longer delays to their care when this healthcare worker needed to take long term leave. Other healthcare worker participants fully supported the MDT approach, stating FND patients need *"specialist services, specialist and multi professional people, specialist teams, people who have that experience or have that knowledge"* [HCW8]. This highlights the need for a more concerted approach to the clinical management of FND, potentially solved by the utilisation of MDTs.

While calls for an MDT approach have occurred from healthcare workers in a variety of clinical settings, it has not yet been instated universally. There are several potential reasons for why this, including financial difficulties in services making it unfeasible to hold extra meetings or recruit more staff to support the MDT approach, challenges in communication across teams and services, a lack of FND-specific training for healthcare workers to suitably and adequately support FND patients across services, and the lack of clinical guidance to streamline the approach and assist in the decision on which services or staff should be involved.

The findings from this research emphasise the debilitating nature of FND, with many patients unable to stay in employment, instead needing to adapt their homes and travel arrangements so they are able to move around safely. While the utilisation of MDTs appears to be the next step forward in improving the clinical management of FND throughout UK services, there is a need for healthcare services to recognise that all areas of rehabilitation need to be offered to FND patients. Vocational rehabilitation, alongside support in accessing benefits and understanding disability support, was requested by all three population groups to be implemented into services, as well as having a specialist FND nurse (similar to cancer support nurses) to help patients understand their FND diagnosis and provide support during the clinical management of symptoms. Having this support in place will provide patients with the knowledge of the next steps of the clinical management of FND, as well as financial and employment information.

The results from this thesis highlight the impact of caregiving duties on informal caregivers. While frameworks have been developed to support caregivers (NHS England, 2019), caregivers participating in the survey and interview studies reported being unsupported by services, and were frequently overwhelmed and burdened by their caring role without being able to ask for support. These findings are similar to studies exploring caregiving duties for other complex health conditions (such as stroke), however, when caregivers were provided with appropriate support, they were found to have stronger psychological wellbeing (Kazemi et al., 2021). In addition, caregiver participants frequently found their caregiving duties to be both mentally and physically taxing. Caregivers (recruited to the survey and interview studies) were classed as informal, meaning they were not employed or paid for the support they provide. Informal caregivers are typically not trained or adequately equipped to undertake physical tasks, such as lifting a person. Therefore, it is not surprising that some caregivers needed to access physiotherapy or other health services, due to the injuries they sustained while providing support. The lack of support and training offered to caregivers may have a detrimental impact, as many are in a position of becoming injured or experiencing burn out, due to having to manage full time caring duties, while also being in employment and managing other family duties. Therefore, services need to implement support for caregivers, or consider bespoke caregiver support where appropriate (e.g. a caregiver providing care for a child may need different support than one who provides care for an elderly adult), or signpost caregivers to groups or organisations who can suitably support them (for example, providing short-term respite, a place to meet and talk to other caregivers, or suitable training). This will ensure patients are receiving safe support at home while also providing support to caregivers.

Although this thesis has only focused on FND in UK clinical settings, the research findings presented may be transferrable to other settings and populations. Patients with other complex conditions, such as fibromyalgia and chronic fatigue syndrome, and their caregivers may resonate with the experiences shared throughout this thesis, due to the stigmatisation linked to the health conditions and outdated beliefs that the conditions are not ‘real’, the patient is malingering, or they are not taken seriously by healthcare workers (Häuser and Fitzcharles, 2018, Griffith and Ryan, 2015). Similarly, the findings may also be transferrable to other countries with a similar healthcare system to the UK (such as Italy, Spain, Portugal and New Zealand), who at the time of writing also do not have an FND-specific clinical guideline in place. The findings from this work are applicable to informal caregivers who provide support to patients with complex and/or chronic conditions as they may also face injuries or burn out due to a lack of support or training.

The findings from this thesis may also have implications for future policy. While the interview study found that adult patients with FND were supported at work when undergoing their FND diagnosis and beyond, adolescents were not adequately supported at school. Indeed, caregivers disclosed how schools refused to complete health and safety assessments, expect children to be isolated in a separate room away from both their peers and teachers, or not allow them to study from home when they were struggling with their symptoms. Therefore, these findings may influence decision-making and policies on how children and adolescents with chronic and complex health conditions are supported in their educational attainment. Further, the findings from the survey and interview studies highlight how funds should be provided to not only support the development of suitable clinical guidelines for FND, but to also decrease time to diagnosis and treatment of FND, as a delay in diagnosis and treatment has a negative impact on a patient's clinical outcomes.

The implications presented above are the first steps to improve the clinical management of FND in UK health services, and may ensure it is prioritised as a health condition. FND is the second most common reason for a patient to attend a neurology service (Stone et al., 2010), yet it is not taken as a serious condition, and is still shrouded in mystery and stigma. However, it is worth reflecting on the potential risk these implications may place on UK health services if they were implemented. For example, introducing an MDT approach to services may improve waiting times and reduce referral times, as it is one central service providing care, yet this way of working may lead to further strain on a service's limited budget. Indeed, the lack of investment in health services has already been reported in relation to risk staff productivity and quality of patient care (The Health Foundation, 2019). Therefore, placing further strain on a service could lead to a decrease in high-quality care being delivered to patients.

It would be prudent to provide FND-specific training for healthcare workers situated in wider health services to increase awareness and understanding of the condition. However, due to the NHS currently facing staff shortages (UK Parliament, 2022), and also the increase in burnout being reported by the NHS workforce (The Health Foundation, 2023), implementing extra training may be unrealistic. Similarly, encouraging collaboration and communication between services would be a sensible and overall productive endeavour, as it would ensure that patients would not be 'lost in the system' due to a breakdown in communication. Yet with services facing pressure to fit as many appointments in a day as possible to clear the waiting time backlog (British Medical Association, 2023), it may be naïve to presume that a healthcare worker would be able to have enough time to collaborate with other services.

7.4 Future research suggestions

The findings from this thesis highlight a number of possible future research studies in this field. To the author's knowledge, this research is currently the only UK study exploring the clinical management of FND from patient, caregiver and healthcare worker perspectives, as well as mapping the current FND diagnostic assessments and treatments used in UK health services. While a large sample size was recruited from the patient group, and healthcare worker perspectives have been explored in other studies (Sahaya et al., 2012, Whitehead and Reuber, 2012), future research that specifically focuses on caregivers would provide an even greater understanding of the impact of FND on unpaid caregivers. Furthermore, repeating the service mapping exercise across UK services (by utilising data linkage and involving NHS Trusts directly) with a clinically and geographically representative sample would provide up-to-date information and strengthen our comprehension of the current clinical management of FND, while showing trends over time.

Between 2020 and 2021, a priority setting partnership conducted a study (using the James Lind Alliance approach) to determine the research priorities for medically not yet explained symptoms (van der Feltz-Cornelis et al., 2022). While FND was one of the health conditions included in the study, it was not the main focus, nor was determining the clinical priorities of FND. Therefore, it would be prudent to determine the clinical priorities of FND in the UK so best practice can be established. This work could be completed by utilising the Delphi method approach (Dalkey, 1967) involving key stakeholders (such as healthcare workers, charitable organisations and expert patients).

As discussed in Chapter 2, the main diagnostic methods for FND involve exclusion assessments, positive criteria and symptomology. However, new methods are being explored, including assessments for systematic inflammation, serum proteins and biomarkers (Hamrah et al., 2020, Miani et al., 2019). Currently, these methods are being used to assist in the diagnosis of FND, but they cannot be used as a stand-alone assessment. Further research is needed to find proof of mechanism for these new methods, as well as establish their feasibility and acceptability. Further research may also indicate that these new methods can potentially shorten the time for FND diagnosis, and also demonstrate cost-effectiveness, as fewer tests will need to be conducted to support the diagnosis.

The evidence collected and analysed throughout this thesis reveals a need for more rigorous and fully powered, prospective studies to examine diagnostic methods and treatments for FND. Although evidence shows the effectiveness of some diagnostic assessments and treatments for FND, much of the current evidence is underpowered. Therefore, fully powered, randomised controlled trials are needed to establish the clinical- and cost-effectiveness of FND diagnostic assessments and treatments.

Previous research suggests effective communication, positive patient-healthcare worker relationship and clinical management between clinical teams were successful in the diagnosis and treatment of FND (Aybek et al., 2013, Petrochilos et al., 2020). This evidence, alongside the findings reported in this work, demonstrate that further studies exploring the effectiveness of a holistic, multidisciplinary team approach is warranted.

It is clear from this thesis that negative attitudes and beliefs surrounding FND are still prevalent in UK health services. While healthcare workers situated in FND teams and services tend to be knowledgeable on the condition, this thesis found that healthcare workers employed in wider services are more likely to be unaware of FND, or accept it as a valid diagnosis. Therefore, it would be sensible to develop an education or training package (based on current evidence) for healthcare workers, in order to raise awareness and increase understanding on the complexities of FND and how it is clinically managed. A pre-post research design on healthcare worker perspectives and beliefs on FND, in conjunction with attending an FND training session, could be conducted in the future.

Lastly, this research highlights the need for the development of a NICE clinical guideline for the clinical management of FND. Co-production with relevant stakeholders (including NHS Trusts, academic teams, charitable organisations and patient groups) will ensure the developed guideline includes appropriate and applicable information.

7.5 Dissemination plan

Some of this doctoral work has been presented at conferences and published in peer reviewed journals (Varley et al., 2023). Planning the next steps to disseminate the main findings is a worthwhile endeavour. Dissemination is the active process of tailoring information and providing it to a specific audience (Lomas, 1993). Dissemination of research not only includes the traditional route of publishing in a peer reviewed journal, but also presentations (both written and oral), mailings (such as newsletters) and even press releases.

When planning the next steps to disseminate this work, the population groups, which have featured heavily throughout this thesis, have been considered alongside other target audiences (e.g., academics and external organisations such as NICE or the FND Society). These considerations have been put in place as population groups are varied, and some may not be familiar with (or able to access) peer reviewed publications, which are often behind paywalls.

The author aims to publish three additional journal articles in high-quality, peer-reviewed journals between Autumn 2023-Summer 2024. These journal articles will focus on the main results from the survey and interview studies, as well as a secondary analysis of the interview data. To promote the findings from this research, the author will work with the University of York's press office to create a press release. Summaries describing the thesis will be sent to relevant organisations (such as the FND Society and FND Hope UK) to be included in their regular newsletters after the peer reviewed articles are published. Lastly, the findings will be presented at relevant conferences (to be determined when conference dates are released).

It is hoped that the disseminated work will have both an academic and clinical impact. The potential impact includes:

- Providing up-to-date information to boost the current FND evidence base
- Informing future UK clinical guidelines on the clinical management of FND (at the time of writing, there are no plans to develop UK clinical guidelines for FND)
- Informing key stakeholders and the wider public of the effectiveness of FND diagnostic tools and treatments used in the UK
- Reducing healthcare costs by identifying areas of improvement in the clinical management of FND in the UK
- Encouraging good practice in the clinical management of FND in the UK
- Encouraging a shift in how FND research is conducted, to ensure the views of patients, caregivers and relevant healthcare workers are routinely included.

7.6 Conclusion

The aim of this doctoral research was to establish the current UK clinical management of FND, and to explore the experiences of healthcare workers, patients and caregivers in relation to the diagnostic and treatment processes for FND. A mixed-methods approach was employed and found that while a range of diagnostic tools and treatments are available and used in the clinical management of FND, many do not have an evidence base reporting their effectiveness.

The findings from this work emphasise how FND impacts everyone involved in the clinical management of FND, and how the limitations of services and healthcare workers impacted on patients' mental health and clinical outcomes. The thesis indicates a significant disparity across UK health services when supporting FND patients, with patients geographically close to the few FND centres across the UK receiving appropriate support, whereas others were placed on waiting lists over two years long, or 'fell through the cracks' due to communication breakdown between services. Awareness and understanding of FND is slowly increasing in UK services, with some healthcare workers in wider health services having the knowledge and expertise to suitably support FND patients. However, this research emphasises how many FND patients are still facing stigma and negative attitudes when attempting to access support. This issue is not location specific; patients across all four UK countries reported stigma and accusations of malingering from healthcare workers. The development of clinical guidelines, a comprehensive education package, along with the implementation of multidisciplinary teams are recommended to improve the clinical management of FND in the UK.

Appendices

Appendix 1: Levels 6 and 7 evidence breakdown

Reference	Condition of interest	Study design	Diagnostic method (if applicable)	Treatment type (if applicable)	Key findings
Agarwal et al., (2019)	FS	Letter	VEEG monitoring	Repetitive transcranial magnetic stimulation (rTMS).	rTMS is a successful treatment option in the reported case.
Agrawal et al., (2014)	FS	Perspective	N/A	Multi-modular psychotherapy	It is unclear which psychological treatment is most effective for FS patients.
Anderson et al., (2019)	FND	Perspective	N/A	N/A	Physical and occupational therapy may be useful assessments for some patients.
Atnas and Lippold (2013)	FS	Case report	N/A	CBT sessions	Frequency of the patient’s FS from seven to two-three per week.
Barrett-Naylor et al., (2018)	FS	Case series	N/A	ACT	Reduction in seizure frequency were reported after ACT.
Baslet and Hill (2011)	FS	Case report	N/A	Acceptance and commitment therapy (ACT) - individual and group sessions	The patient very rapidly recovered most of their autobiographical memory and their tremors no longer occurred.
Burke et al., (2018)	FND	Letter	N/A	Neurostimulation treatment (TMS)	TMS excitability measures of the left motor cortex increased in parallel with clinical improvement of right-sided functional weakness.
Burke et al., (2020)	FND	Opinion	N/A	Placebo	A mechanism-based rationale that supports the potential use of placebo effects for the treatment of FND was provided in the record.
Chen et al., (2017a)	FND	Case report	Diagnosed by a psychiatrist (no further information provided)	Psychotherapy	Psychotherapy was effective in reducing the patient’s FS.

Reference	Condition of interest	Study design	Diagnostic method (if applicable)	Treatment type (if applicable)	Key findings
Choudhry et al., (2020)	FND	Case study	EEG	The expanded CBT model for medically unexplained symptoms	The patient reported to have 75% improvement.
Cope et al., (2017b)	FND	Case report	Diagnosis confirmed by consultant neurologist	Psychological therapy and EMDR	Psychological treatment-as usual plus EMDR led to improvements for both patients.
de Vroege et al., (2017)	FND	Case report	Psychiatric examination (no further information provided)	Neuropsychological treatment (TPM)	After TPM the patient’s conversion disorder went into remission.
Gaillard et al., (2012)	FND	Case report	N/A	Electroconvulsive therapy (ECT)	Small improvements were found, however, the patient relapsed after the last ECT session was completed.
Graham et al., (2018)	FND	Case series	Diagnosis delivered by neurologist (no further information provided)	ACT	The majority of patients had reliable improvements in symptom interference and/or mood.
Hardin and Carson (2019)	FNSD	Case presentation	N/A	Interdisciplinary treatment (psychotherapeutic interventions, physical therapy, and occupational therapy)	The proposed model may allow for a quick deployment of an appropriate treatment approach for patients with FNSD.
Hsieh and Deshpande, (2020)	FND	case report	During the assessment, the patient demonstrated a positive Hoover’s sign. In addition to this, a genetic test was completed. This assessment confirmed a diagnosis of FND.	A specialised FND treatment programme (including CBT, specialist physiotherapy, planned physical activities, and psychoeducation)	The multidisciplinary treatment approach led to positive outcomes, including full restoration of active movement in the right ankle, independence with mobility and improvements in outcome measures.
Joos (2019)	FND	Letter	N/A	Group integrated inpatient rehabilitation	The patients started to develop trust and found ways to cope with their life situation more actively.
Kamil et al., (2019)	FS	Case report	EEG	CBT	Early diagnosis and clinical management of FS is imperative and should be focused on CBT.
Kanemoto et al., (2017)	FS	Special report	N/A	N/A	Although recent scientific findings about the aetiology and treatment of FS are likely to be universally true,

Reference	Condition of interest	Study design	Diagnostic method (if applicable)	Treatment type (if applicable)	Key findings
					optimal solutions or improvements will have to be specific to individual countries, reflecting the different cultural traditions of each.
Knight (2017)	FS	Case study	N/A	Hypnosis	The patient's seizures reduced in number and intensity to the point where they had had no seizures in nearly five weeks.
Kusmakar et al., (2018)	FS	Conference paper	Wrist-worn accelerometer device	N/A	When tested, the algorithm correctly detected all seizure events (8 ES, and 8 FS) and 260 (92.85%) of 280 ADLs with 20 false alarms. The algorithm correctly classified 8 (100%), and 6 (75%) of the detected seizure events as FS and ES, respectively.
Leandertz (2018)	FND	Case study	N/A	Vibroacoustic therapy	The patient showed improvement and developed strategies to help in everyday situations.
Lidstone et al., (2020a)	FND	Letter	N/A	N/A	A clear, early diagnosis can have a strong positive impact on the patient's symptoms, prognosis and quality of life.
Lidstone et al., (2020b)	FMD	Viewpoint/ pilot clinic	N/A	Multidisciplinary treatment (neurology, psychiatry, and physical therapy)	64% of patients had "much" or "very much" improved, which was sustained at 3 months.
McKee et al., (2018)	FND	Perspective	N/A	N/A	FND treatment can start in the hospital with an early interdisciplinary approach and a thoughtful communication of the diagnosis
Myers and Zandberg (2017)	FS	Case report	Patient underwent inpatient testing vEEG monitoring) and neuropsychological testing to confirm FS	Prolonged Exposure Therapy	The patient achieved full remission of all FS symptoms.

Reference	Condition of interest	Study design	Diagnostic method (if applicable)	Treatment type (if applicable)	Key findings
Nielsen et al., (2015)	FMD	Viewpoint	N/A	Physiotherapy	Physiotherapy treatment for FMD is acceptable to patients and is becoming increasingly researched.
Noll-Hussong et al., (2014)	FND	Case report	N/A	Caloric vestibular stimulation (CVS)	Results found that lateralized cold vestibular caloric stimulation was an effective treatment.
O'Neal and Baslet (2018)	FND	Perspective	N/A	N/A	When communicating the FND diagnosis, the diagnosing healthcare worker should contact relevant professionals (e.g., mental health clinician, physical therapists) to agree the best treatment options.
Rancourt and Darkes (2019)	FND	Case report	A review of the patient’s medical files in conjunction with information was gathered	DBT	At the end of treatment, the patient had improved motor ability and clinically significant improvements in their reported symptoms of MDD (per the Patient Health Questionnaire–9) and PTSD (per the PTSD Checklist–Civilian Version).
Reuber (2019)	FS	Letter	N/A	N/A	The article explained how to (and how not to) communicate the FS diagnosis to patients.
Stone (2016)	FND	Opinion	N/A	N/A	A successful neurological consultation should be the beginning of treatment.
Stone (2019)	FND	Website	N/A	N/A	N/A
Stone et al., (2014)	FNSD	Communication	N/A	Therapeutic sedation	Therapeutic sedation and medication (propofol) may be a useful treatment for FNSD.
Wen et al., (2019)	FND	Conference abstract	Telestroke service	N/A	The unadjusted telemedicine CD diagnostic accuracy was 0.98.

Key: FND = functional neurological disorder; FS = functional seizures; FNSD = functional neurological symptom disorder; FMD = functional movement disorder

Appendix 2: Search Strategies

MEDLINE and MEDLINE in Process (Ovid)

1	exp conversion disorder/
2	Conversion disorder$.ab,ti.
3	(Functional neurological disorder* or functional neurological symptom* or FND).ab,ti.
4	(Functional movement disorder* or Functional neurological symptom disorder* or FNSD).ab,ti.
5	Neurological conversion symptom*.ab,ti.
6	exp dissociative disorders/
7	Dissociative neurological disorder*.mp. or Dissociative neurological symptom*.ab,ti. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh]
8	(psychogenic seizure* or non-epileptic seizure* or dissociative seizure* or non-epileptic attack* or non-epileptic attack* or pseudoseizure* or PNES).ab,ti.
9	Functional cognitive symptom*.mp. or Functional cognitive motor skill*.ab,ti. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh]
10	Conversion symptoms*.ab,ti.
11	Functional weakness*.ab,ti.
12	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11
13	exp therapy/
14	exp Guideline/
15	exp Diagnosis/
16	"clinical management".ab,ti.
17	13 or 14 or 15 or 16
18	12 and 17
19	((Alzheimer* disease) or cancer or epilepsy or stroke or surgery or autis*).ab,ti.
20	18 NOT 19

PsycInfo (Ovid)

1	exp conversion disorder/
2	Conversion disorder$.ab,ti.
3	(Functional neurological disorder* or functional neurological symptom* or FND).ab,ti.
4	(Functional movement disorder* or Functional neurological symptom disorder* or FNSD).ab,ti.
5	Neurological conversion symptom*.ab,ti.
6	exp dissociative disorders/
7	Dissociative neurological disorder*.mp. or Dissociative neurological symptom*.ab,ti. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh]
8	(psychogenic seizure* or non-epileptic seizure* or dissociative seizure* or non-epileptic attack* or non-epileptic attack* or pseudoseizure* or PNES).ab,ti.
9	Functional cognitive symptom*.mp. or Functional cognitive motor skill*.ab,ti. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh]
10	Conversion symptoms*.ab,ti.
11	Functional weakness*.ab,ti.
12	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11
13	exp therapy/
14	exp Guideline/
15	exp Diagnosis/
16	"clinical management".ab,ti.
17	13 or 14 or 15 or 16
18	12 and 17
19	((Alzheimer* disease) or cancer or epilepsy or stroke or surgery or autis*).ab,ti.
20	18 NOT 19

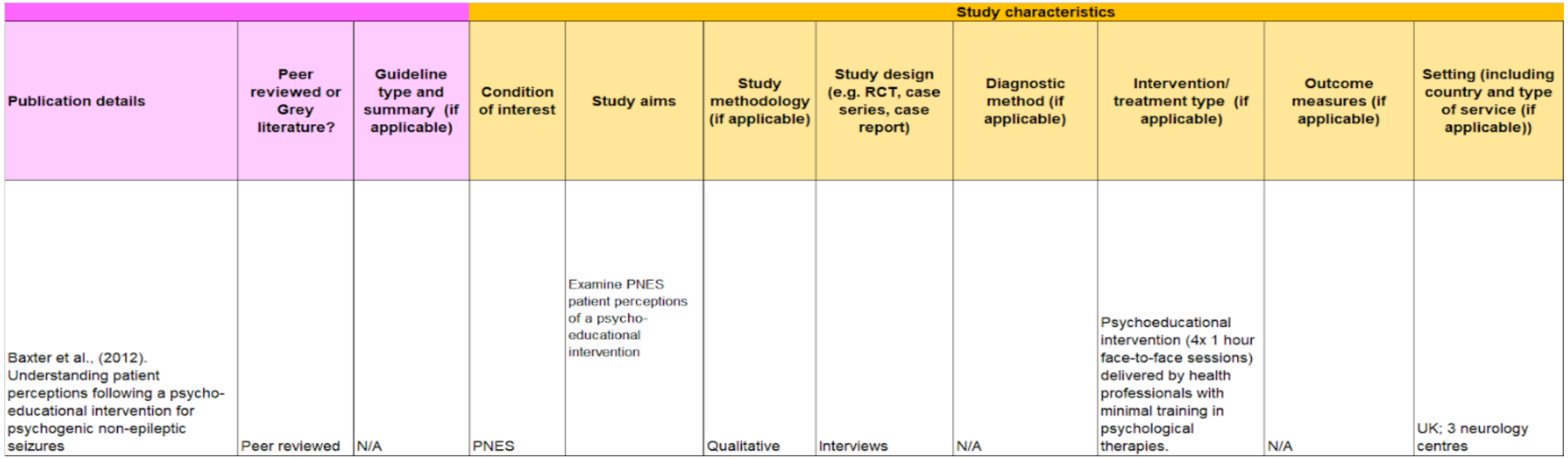
Cochrane Database of Systematic Reviews (CDSR)

#1	MeSH descriptor: [Conversion Disorder] explode all trees
#2	(Conversion disorder*):ti,ab,kw
#3	((Functional neurological disorder*) OR (functional neurological symptom*) OR FND):ti,ab,kw
#4	((Functional movement disorder*) OR (Functional neurological symptom disorder*) OR FNSD):ti,ab,kw
#5	(Neurological conversion symptom*):ti,ab,kw
#6	MeSH descriptor: [Dissociative Disorders] explode all trees
#7	((Dissociative neurological disorder*) OR (Dissociative neurological symptom*)):ti,ab,kw
#8	((psychogenic seizure*) OR (non-epileptic seizure*) OR (dissociative seizure*) OR (non-epileptic attack*) OR (non-epileptic attack*) OR pseudoseizure* OR PNES):ti,ab,kw
#9	((Functional cognitive symptom*) OR (Functional cognitive motor skill*)):ti,ab,kw
#10	(Conversion symptoms*):ti,ab,kw
#11	(Functional weakness*):ti,ab,kw
#12	#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9 OR #10 OR #11
#13	MeSH descriptor: [Therapeutics] explode all trees
#14	MeSH descriptor: [Guideline] explode all trees
#15	MeSH descriptor: [Diagnosis] explode all trees
#16	clinical management
#17	#12 OR #13 OR #14 OR #15 OR #16
#18	#12 AND #17
#19	(Alzheimer* disease) OR cancer* OR epilepsy OR stroke OR surgery OR autis*
#20	#18 NOT #19

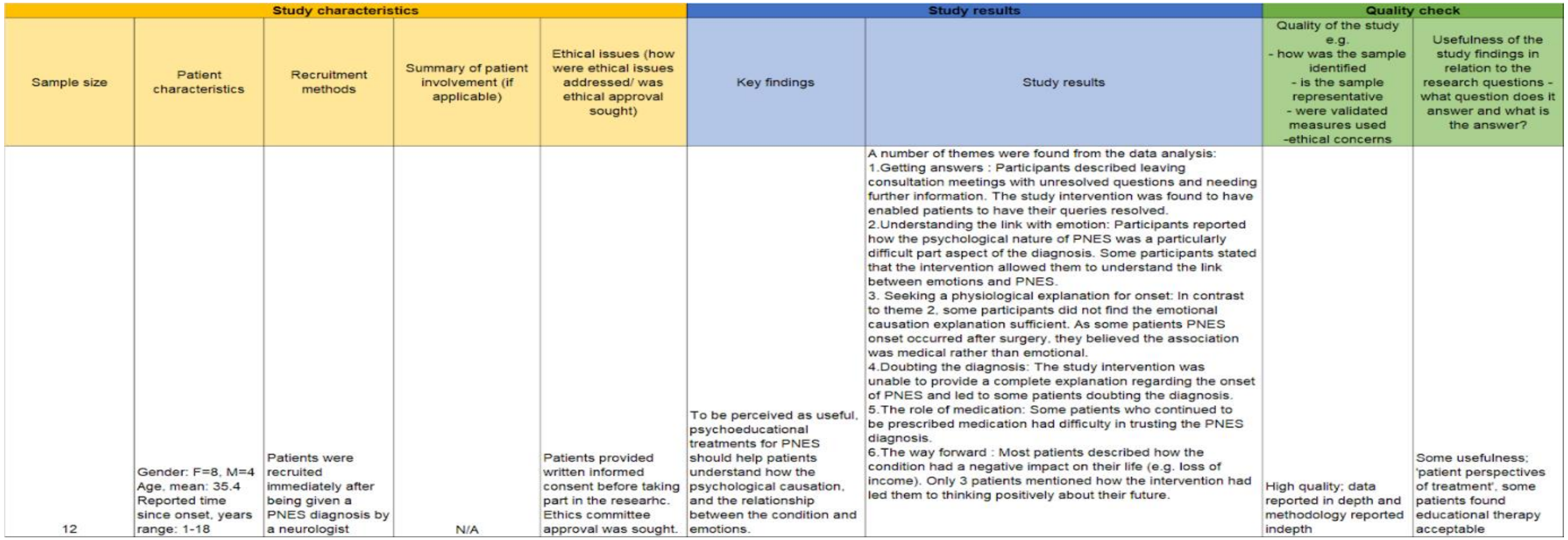
Google Scholar

1.	intitle: (“conversion disorder”)
2.	intitle: ("Functional neurological disorder*") OR ("functional neurological symptom*") OR "FND”
3.	intitle: ("Functional movement disorder*") OR ("Functional neurological symptom disorder*") OR "FNSD”
4.	intitle: (“Neurological conversion symptom*”)
5.	intitle: (“dissociative disorders”)
6.	intitle: (“Dissociative neurological disorder*”) OR (“Dissociative neurological symptom*”)
7.	intitle: (“psychogenic seizure*”) OR (“non-epileptic seizure*”) OR (“dissociative seizure*”) OR (“non-epileptic attack*”) OR (“non-epileptic attack*”) OR “pseudoseizure*” OR “PNES”
8.	intitle: (“Functional cognitive symptom*”) OR (“Functional cognitive motor skill*”)
9.	intitle: (“Conversion symptoms*”)
10.	intitle: (“Functional weakness*”)

Appendix 3: Data Chart Example



			Study characteristics							
Publication details	**Peer reviewed or Grey literature?**	**Guideline type and summary (if applicable)**	**Condition of interest**	**Study aims**	**Study methodology (if applicable)**	**Study design (e.g. RCT, case series, case report)**	**Diagnostic method (if applicable)**	**Intervention/ treatment type (if applicable)**	**Outcome measures (if applicable)**	**Setting (including country and type of service (if applicable))**
Baxter et al., (2012). Understanding patient perceptions following a psycho-educational intervention for psychogenic non-epileptic seizures	Peer reviewed	N/A	PNES	Examine PNES patient perceptions of a psycho-educational intervention	Qualitative	Interviews	N/A	Psychoeducational intervention (4x 1 hour face-to-face sessions) delivered by health professionals with minimal training in psychological therapies.	N/A	UK; 3 neurology centres



Study characteristics					Study results		Quality check	
Sample size	Patient characteristics	Recruitment methods	Summary of patient involvement (if applicable)	Ethical issues (how were ethical issues addressed/ was ethical approval sought)	Key findings	Study results	Quality of the study e.g. - how was the sample identified - is the sample representative - were validated measures used -ethical concerns	Usefulness of the study findings in relation to the research questions - what question does it answer and what is the answer?
12	Gender: F=8, M=4 Age, mean: 35.4 Reported time since onset, years range: 1-18	Patients were recruited immediately after being given a PNES diagnosis by a neurologist	N/A	Patients provided written informed consent before taking part in the researhc. Ethics committee approval was sought.	To be perceived as useful, psychoeducational treatments for PNES should help patients understand how the psychological causation, and the relationship between the condition and emotions.	A number of themes were found from the data analysis: 1.Getting answers : Participants described leaving consultation meetings with unresolved questions and needing further information. The study intervention was found to have enabled patients to have their queries resolved. 2.Understanding the link with emotion: Participants reported how the psychological nature of PNES was a particularly difficult part aspect of the diagnosis. Some participants stated that the intervention allowed them to understand the link between emotions and PNES. 3. Seeking a physiological explanation for onset: In contrast to theme 2, some participants did not find the emotional causation explanation sufficient. As some patients PNES onset occurred after surgery, they believed the association was medical rather than emotional. 4.Doubting the diagnosis: The study intervention was unable to provide a complete explanation regarding the onset of PNES and led to some patients doubting the diagnosis. 5.The role of medication: Some patients who continued to be prescribed medication had difficulty in trusting the PNES diagnosis. 6.The way forward : Most patients described how the condition had a negative impact on their life (e.g. loss of income). Only 3 patients mentioned how the intervention had led them to thinking positively about their future.	High quality; data reported in depth and methodology reported indepth	Some usefulness; 'patient perspectives of treatment', some patients found educational therapy acceptable

Appendix 4: Included reviews in the scoping review

Author	Country and setting	Study design	Study aims	Condition of interest	Diagnostic method	Treatment/ intervention	Patient perspectives	Main findings
Abdelnour and El-Nagi (2017)	N/A	Narrative review	Review the role of neuroimaging in establishing an FND diagnosis	FND	Reviews the following: • Positive signs • Co-contraction • computed tomography (CT) • Functional magnetic resonance imaging • La belle indifference • magnetic resonance imaging • Positron emission tomography • Single photon emission computed tomography	N/A	N/A	There is no single test that positively supports an FND diagnosis. Numerous functional neuroimaging studies report that neuro-correlates that are useful to discern FND from malingering.
Ali et al., (2015)	N/A	Review	Review the literature on the clinical management of CD	CD	N/A	Review includes: • Psycho-therapy • Physical therapy • Medication	Patient-healthcare worker relationship	Building a good therapeutic alliance is crucial for successful treatment. Regular follow-up appointments in conjunction with treatments show favourable results.
Allen and Woolfolk (2013)	N/A	Review	Review the literature on CBT for CD	CD	N/A	CBT	Treatment	Further research is needed to test the effectiveness of CBT for CD.
Baslet et al., (2015)	N/A	Review	Review a framework for treatment of FS	FS	N/A	Review includes: • CBT	Patient adherence	Adherence to treatment is imperative to managing FS.

Author	Country and setting	Study design	Study aims	Condition of interest	Diagnostic method	Treatment/ intervention	Patient perspectives	Main findings
						• Mindfulness-based psycho-therapy • Medication		CBT is successful in treating CD symptoms.
Baslet et al., (2020)	N/A	System-atic review	Define the clinical factors and diagnostic tests which assist in a FS diagnosis	FS	Reviewed the following: • vEEG • EEG • Semiological signs	N/A	N/A	EEG and vEEG are the gold standard of diagnostic tools for FS and have the highest level of diagnostic certainty. Induction techniques can assist in the diagnosis of FS.
Bermeo-Ovalle and Kanner (2017)	N/A	Book chapter	Review the role of the neurologist in the clinical management of FS	FS	N/A	N/A	Patient-healthcare worker relationship	Neurologists are an essential member of an MDT and responsible in assisting in the clinical management of FS. Healthcare workers should ensure that patients and caregivers understand and accept the FS diagnosis.
Butler et al., (2020)	N/A	System-atic review	Review research involving the use of psychedelics in FND	FND	N/A	Psychedelic treatments: • LSD • Psilocybin • Mescaline	N/A	Over two-thirds of patients recruited to the included studies were found to have made some recovery with psychedelic treatment and psychotherapy.

Author	**Country and setting**	**Study design**	**Study aims**	**Condition of interest**	**Diagnostic method**	**Treatment/ intervention**	**Patient perspectives**	**Main findings**
Carlson and Nicholson Perry (2017)	N/A	Systematic review and meta-analysis	Evaluate the utility of psychological interventions for FS	FS	N/A	Review includes: • CBT • Psychodynamic therapy • Paradoxical intention therapy • Mindfulness • Psychoeducation • Eclectic psychotherapy	N/A	Patients accessing psychological interventions for FS may have a reduction in seizures compared to patients who do not receive psychotherapy.
Carson et al., (2012)	N/A	Review	To report relevant literature on functional neurological symptoms	FND symptoms	Functional imaging	Review includes: • Pharmacotherapy • Psychological therapies	Diagnosis and treatment options	New diagnostic methods are being explored. The field is leaning towards using other methodologies to investigate clinical signs.
Chen and LaFrance (2016)	N/A	Review	Explore the evaluation process involved in FS diagnosis	FS	Review includes: • vEEG monitoring • Ambulatory EEG • Home video recording	N/A	Patient-healthcare worker relationship	The diagnosis of FS can be difficult but using a multi-component approach can facilitate the clinical management of the condition.
Chen et al., (2017b)	N/A	Review	Investigate the evaluation process involved in the diagnosis of FS	FS	Review includes: • Semiological signs • Physical exam • vEEG monitoring • Historical examination	N/A	N/A	A FS diagnosis can be reliably made using vEEG findings, historical exam, and physical exam.

Author	Country and setting	Study design	Study aims	Condition of interest	Diagnostic method	Treatment/ intervention	Patient perspectives	Main findings
Cope et al., (2017b)	N/A	Review	Discuss why ACT may be an effective treatment for FS	FS	N/A	ACT	N/A	ACT is potentially an effective treatment option for FS patients.
Cope et al., (2018)	N/A	Systematic review	Review the evidence of eye movement desensitisation and reprocessing (EMDR) as an FND treatment	FND	N/A	EMDR	N/A	Four of the five participants in the included studies were treated successfully using EMDR.
Cottencin (2014)	N/A	Review article	Provide an overview of psychiatric and psychotherapeutic aspects of conversion disorder	CD	N/A	N/A	Patient-healthcare worker relationship	The coordination of healthcare workers is needed for effective treatment
Czarnecki and Hallett (2012)	N/A	Review	Review the management of functional movement disorder	Functional movement disorder	Review includes: • Electrophysiological tests • Neuroimaging	Review includes: • Medication • CBT • Physical therapy	N/A	More research is needed to develop treatments for FMD
Daum et al., (2014)	N/A	Systematic review	Review evidence regarding the sensitivity and specificity of positive signs for CD	CD	Positive signs	N/A	N/A	Only 14 positive clinical signs have been validated and generally have high specificity but low sensitivity.
Deeley (2016)	N/A	Book chapter	Discuss the history and	FND	N/A	Hypnosis	N/A	The majority of hypnosis evidence is

Author	Country and setting	Study design	Study aims	Condition of interest	Diagnostic method	Treatment/ intervention	Patient perspectives	Main findings
			current evidence of hypnosis as a treatment for FND					from case series and case studies.
Devinsky et al., (2011)	N/A	Review	Provide an overview of the FS diagnostic evaluation	FS	Reviews the following: • vEEG • EEG • Home video recordings • Provocative testing (including verbal suggestion, hypnosis, body part compression) • MRI • Neurophysiological assays • Single-photon emission CT • Psychiatric evaluation	N/A	N/A	vEEG is the diagnostic gold standard for FS, but diagnostic accuracy can be improved by considering the patient's neurological and psychiatric history.
Edwards (2018)	N/A	Book chapter	Evaluate current evidence regarding the clinical management of functional gait disturbance	FNS	N/A	Review includes: • Diagnostic explanation • Physical therapy	N/A	A diagnostic explanation that is understood and accepted by the patient is essential for successful treatment.
Espay et al., (2018)	N/A	Review	Review treatments for FND	FND	N/A	Review includes:	N/A	Successful treatment relies on a diagnostic delivery which gives

Author	Country and setting	Study design	Study aims	Condition of interest	Diagnostic method	Treatment/ intervention	Patient perspectives	Main findings
						- Diagnostic explanation - CBT - Physical therapy		the patient an insight into the condition.
Frauenheim (2018)	N/A	Review	Provide information on whether there are reliable criteria and treatments for FS	FS	vEEG	- Psychoeducation - Psychotherapy	N/A	How the diagnosis is presented to the patient affects the likelihood of them accepting or denying the diagnosis.
Fritzsche et al., (2013)	N/A	Review	Review the diagnosis and treatment of FS	FS	vEEG	Psychotherapy	N/A	vEEG provides a highly reliable diagnosis for FS. Psychotherapy has been reported to reduce the frequency of dissociative seizures by at least 50%.
Furlan and Alciati (2020)	N/A	Book chapter	Provide an update on the clinical management of FS	FS	vEEG	Review includes: - Diagnosis explanation - CBT - Psychotherapy	N/A	An empathic communication of the diagnosis and transparent information on the most appropriate treatments should be given to patients and caregivers.
Garcin (2018)	N/A	Review	Provide an update on diagnostic and treatment	FND	Positive signs	Review includes: - Transcranial Magnetic	N/A	A multidisciplinary approach to diagnosing and treating FND is important. If needed,

Author	Country and setting	Study design	Study aims	Condition of interest	Diagnostic method	Treatment/ intervention	Patient perspectives	Main findings
			methods for FND			Stimulation (TMS) • Physical therapy • CBT • Psycho-dynamic therapy		further treatment can be proposed (e.g., TMS or hypnosis)
Gasca-salas and Lang (2016)	N/A	Review	Review the rating scales and diagnostic criteria for FS and FMD	FND	Review includes: • Positive signs • vEEG	N/A	N/A	The presence of positive signs should be relied on for FMD and FS diagnosis.
Gilmour et al., (2020)	N/A	Review	Examine strategies for the clinical management of FND	FND	Review includes: • vEEG • EEG	Review includes: • Diagnostic explanation • Physical therapy • CBT • Medication • Non-invasive brain stimulation	N/A	FND requires thorough diagnostic assessments, open and holistic discussion of the diagnosis, and tailored treatments for each patient.
Goldstein and Mellers (2016)	N/A	Book chapter	Discuss the psychological treatments used to treat FND	FND	N/A	Review includes: • CBT • Psychoeducation	N/A	The diagnosis should be given clearly to patients and a multidisciplinary approach to treatment should be used.
Greiner et al., (2016)	N/A	Review	Provide a treatment-focused review for FND	FND	N/A	Review includes: • Medication	N/A	Treatment led by a multidisciplinary team show promising results.

Author	Country and setting	Study design	Study aims	Condition of interest	Diagnostic method	Treatment/ intervention	Patient perspectives	Main findings
						• Physio-therapy • CBT • Repetitive TMS (rTMS)		
Joos et al., (2017)	N/A	Review	Discuss the differential diagnosis of FS	FS	vEEG	N/A	Patient-healthcare worker relationship	It is important to use vEEG to rule-out epilepsy
LaFaver, (2020b)	N/A	Review	To provide an overview of the evidence-based and emerging FMD treatments.	FMD	N/A	Review includes: • Physio-therapy • Occupation-al therapy • Speech therapy • CBT • Medication • Botulinum toxin • rTMS	N/A	There is insufficient evidence for the effectiveness of FMD treatments. There is a need for RCTs to compare the available treatments.
LaFrance et al., (2016)	N/A	Review	Report the evaluation process for FS diagnosis	FS	Review includes: • Eyewitness history • vEEG monitoring • Home video recording	N/A	N/A	Eyewitness history, home video recording, and vEEG monitoring can establish a FS diagnosis with a high level of confidence.
LaFrance and Goldstein (2017)	N/A	Book chapter	Review FS treatments	FS	N/A	Review includes: • Psycho-therapy	N/A	Psychological therapy and psychoeducational approaches may be

Author	Country and setting	Study design	Study aims	Condition of interest	Diagnostic method	Treatment/ intervention	Patient perspectives	Main findings
						• Medication • Hypnosis • CBT • Psycho-education		effective FS treatments. Further research is needed to assess the effectiveness due to current studies using limited sample sizes.
Lai (2013)	N/A	Literature review	Review the evidence on treatment for conversion disorder	CD	N/A	Review includes: • Psycho-therapy • Hypnosis • rTMS	N/A	rTMS is a promising new treatment for FMD.
Lehn et al., (2016)	N/A	Review	Review recent FND studies	FND	Review includes: • EEG • vEEG	Review includes: • Physio-therapy • CBT • TENS • Biofeedback • Sedation • TMS	N/A	Positive diagnostic criteria should be used and a transparent explanation should be given to the patient.
Ludwig et al., (2016)	N/A	Review	Review the physical signs of functional coma	FNSD	Review includes: • Positive signs • EEG	Sedation with propofol	N/A	Diagnosis using exclusion should not be used, clinical history and positive signs are more appropriate.
Martlew et al., (2014)	N/A	System-atic review	Assess the effectiveness of behavioural and psychological	FS	N/A	Review includes: • CBT • Hypnosis	N/A	There is little evidence to show how effective treatments are for FS.

Author	Country and setting	Study design	Study aims	Condition of interest	Diagnostic method	Treatment/ intervention	Patient perspectives	Main findings
			treatments for FS			• Paradoxical intention therapy • Psycho-therapy		
Nicholson and Voon (2016b)	N/A	Review	To assess the evidence base focused on magnetic stimulation and sedation	FND	N/A	Transcranial magnetic stimulation (TMS) and sedation	N/A	There is evidence supporting that TMS is a safe and potentially effective FND treatment. However, the available evidence is largely based on case series. The role of placebo may be significant for the treatment of FND but has not been tested widely in studies.
O'Neal and Baslet (2018)	N/A	Review	Provide a practical approach to treating FND	FND	Review includes: • fMRI • Electromyography • Positive signs	Review includes: • Physical therapy • CBT • Hypnosis	N/A	A multidisciplinary approach is needed to treat FND.
Parain and Chastan (2014)	N/A	Review	Investigate the efficacy of large-field stimulation for FND patients	FND	N/A	Large-field rTMS	N/A	Large-field rTMS is a safe and efficacious intervention for FND patients with difficult-to-treat symptoms.

Author	**Country and setting**	**Study design**	**Study aims**	**Condition of interest**	**Diagnostic method**	**Treatment/ intervention**	**Patient perspectives**	**Main findings**
Plioplys et al., (2017)	N/A	Book chapter	Report the healthcare workers response to diagnosing FS	FS	N/A	N/A	Healthcare worker perspective	It was found that many healthcare workers have a negative attitude to providing healthcare for them and that they are difficult to understand and clinically manage. This negative attitude can impact the therapeutic relationship and lead to premature termination of treatment. Education for healthcare workers and utilising a patient-centred approach to clinical management is needed for a successful therapeutic relationship.
Pollak et al., (2014)	N/A	Systematic review	Review studies of TMS to treat FNS	FNS	N/A	TMS	N/A	Only non-placebo-controlled studies have been conducted exploring TMS as an effective treatment for FNS. Nearly all included studies found TMS to be successful.

Author	**Country and setting**	**Study design**	**Study aims**	**Condition of interest**	**Diagnostic method**	**Treatment/ intervention**	**Patient perspectives**	**Main findings**
Poole et al., (2010)	N/A	Systematic review	Review the available evidence which report on the use of drug interviews for CD symptoms	CD	N/A	Abreaction	N/A	The evidence studying the effectiveness of abreaction is of low quality. However, abreaction may be useful in the treatment of acute and treatment-resistant CD.
Popkirov et al., (2015)	N/A	Systematic review	Review the use of Suggestive seizure induction (SSI) for FS	FS	SSI	N/A	N/A	SSI can have a strong diagnostic yield and is an effective tool to diagnose FS.
Popkirov et al., (2019)	N/A	Review	Examine the overlap between FND and CRPS	FND	N/A	Review includes: • Explanation-based physical therapy • Multimodal physiotherapy • Psychological therapy	N/A	Explanation-based physical therapy is an effective treatment for FND
Popkirov et al., (2020)	N/A	Review	Provide a review of examination techniques to identify functional weakness	Functional weakness	Review includes: • Positive signs • MRI	N/A	N/A	Clear positive signs should support an FND diagnosis. An FND diagnosis relying on psychosocial factors, negative imaging, or

Author	**Country and setting**	**Study design**	**Study aims**	**Condition of interest**	**Diagnostic method**	**Treatment/ intervention**	**Patient perspectives**	**Main findings**
								psychiatric comorbidity may lead to a misdiagnosis. Neuroimaging can support the diagnosis of FND.
Restrepo and Restrepo (2019)	N/A	Review	Review the diagnostic and treatment strategies for FND	FND	Positive clinical signs	Review includes: • rTMS • Hypnosis • CBT • Physiotherapy	N/A	Positive findings should be conducted to diagnosis FND.
Ricciardi and Edwards (2014)	N/A	Review	Provide a summary of the evidence regarding the treatment of FMD	FMD	N/A	Review includes: • Diagnostic explanation • Physio-therapy • CBT • Psycho-therapy • Medication • Placebo • Hypnosis • Trans-cutaneous electrical nerve stimulation (TENS) • TMS • Inpatient multi-	N/A	There are few high-quality studies exploring the effectiveness of treatments for FMD.

Author	Country and setting	Study design	Study aims	Condition of interest	Diagnostic method	Treatment/ intervention	Patient perspectives	Main findings
						disciplinary therapy		
Rosebush and Mazurek, (2011)	N/A	Review	Provide an overview of treatment options and barriers to treatment	CD	N/A	Review includes: • Abreaction • Psychotherapy • Pharmacotherapy	N/A	Psychotherapy (psychodynamic or cognitive-behavioural based) is the main treatment for CD. Barriers to treatment include delayed diagnosis, and the patient not accepting the CD diagnosis.
Sahaya et al., (2011)	N/A	Review	Review the literature on the clinical management of FS	FS	N/A	Review includes: • EEG • MRI	N/A	Although numerous clinical features have been described to assist in the FS diagnosis, vEEG is considered the gold standard diagnostic tool.
Sawchuk et al., (2017)	N/A	Book chapter	Detail models of care for FS patients	FS	N/A	N/A	Barriers	There are significant barriers to FS management, including: diagnostic and treatment barriers, healthcare system barriers, healthcare worker education and knowledge, lack of research evidence. These barriers can be addressed by utilising a holistic care model

Author	Country and setting	Study design	Study aims	Condition of interest	Diagnostic method	Treatment/ intervention	Patient perspectives	Main findings
								involving both the healthcare worker and patient, as well as the healthcare service.
Schmutz (2016)	N/A	Book chapter	Review the difficulties of the clinical management of FS patients	FS	Review includes: • vEEG • EEG • MRI • Psychiatric exam	Review includes: • Diagnostic explanation • Psychological therapy	N/A	FS is a symptom of an underlying psychiatric disorder which can be improved by undergoing treatment.
Schonfeldt-Lecuona et al., (2016)	N/A	Systematic review	Discuss the potential of Non-invasive brain stimulation (NIBS) method in the treatment of CD	CD	N/A	NIBS methods	N/A	There is initial evidence that NIBS (notably rTMS) may be effective in treating CD
Staack and Steinhoff (2015)	N/A	Review	Review the clinical criteria to diagnose FS	FS	vEEG	N/A	N/A	vEEG is the gold standard when diagnosing FS
Stone and Carson (2015)	N/A	Review	Provide a guide for the diagnosis and treatment of FND	FND	Review includes: • History taking • Positive signs	Review includes: • Diagnostic explanation • Physical therapy • Psychological therapy • Hypnosis • Sedation • rTMS	N/A	Diagnosis should focus on using positive methods. Healthcare workers should aim to explain the diagnosis clearly and educate patients.

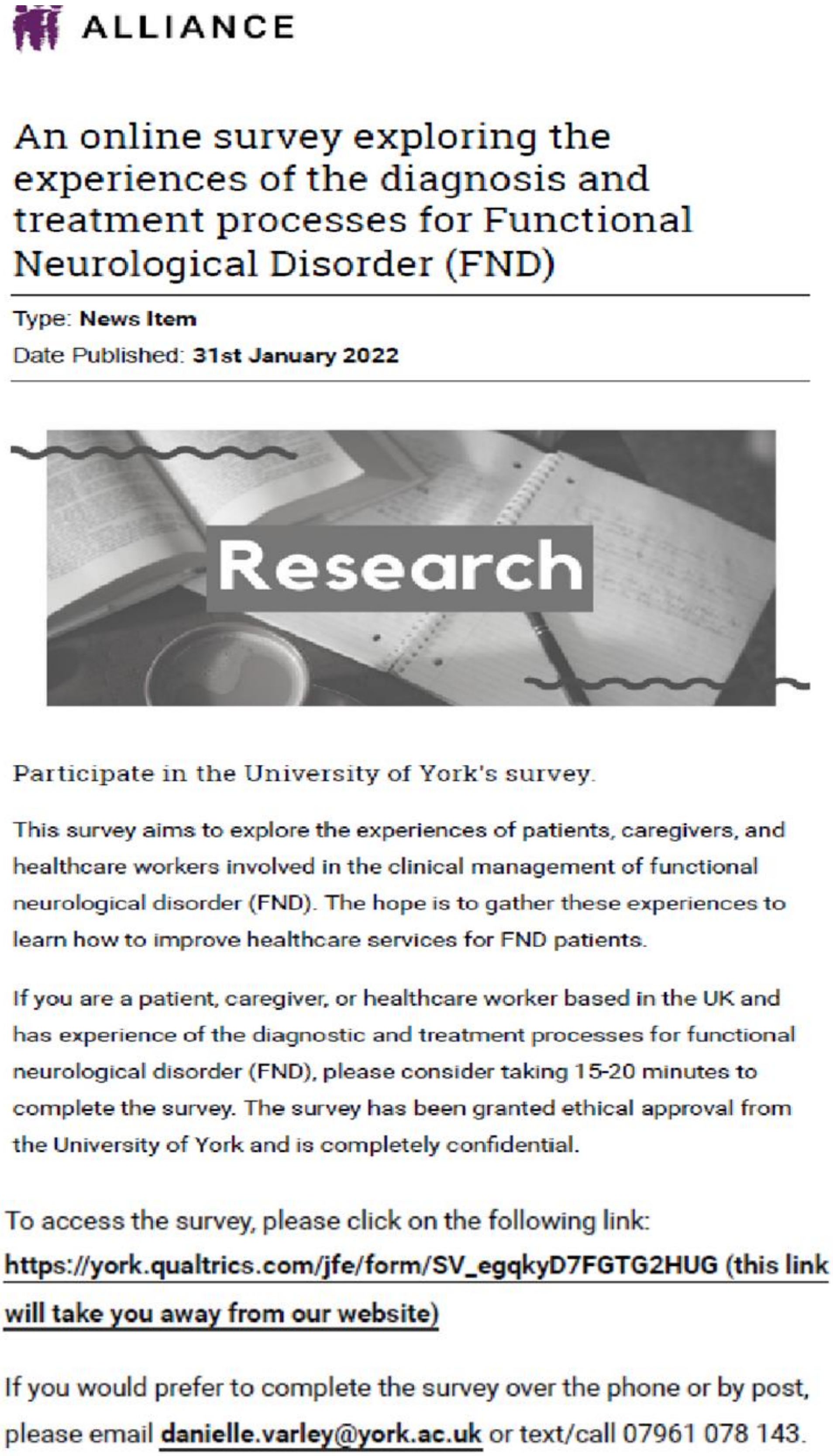
Author	Country and setting	Study design	Study aims	Condition of interest	Diagnostic method	Treatment/ intervention	Patient perspectives	Main findings
Stone and Aybek (2016a)	N/A	Review	Provide an overview of diagnostic instruments for functional weakness	FND	Positive signs	N/A	N/A	Many positive signs exist to support the clinical diagnosis. The functional weakness diagnosis should be made on the basis of a physical examination.
Sundararajan et al., (2016)	N/A	System-atic review	Review non-vEEG candidate biomarkers that may assist the FS diagnosis	FS	Review includes: • Neuroimaging markers • Heart rate and heart rate variability • Prolactin • Cortisol, • Thyrotropin-releasing hormone, • Catecholamine • melatonin • Adrenocorticotropic hormone • Nesfatin-1 • Ghrelin • white blood cell count • Creatine kinase • Creatine • phosphokinase • Neuron-specific enolase • Brain derived neutrotrophic factor • Platelet membrane Serotonin transport	N/A	N/A	No single biomarker was found to successfully differentiate FS from epileptic seizures.

Author	**Country and setting**	**Study design**	**Study aims**	**Condition of interest**	**Diagnostic method**	**Treatment/ intervention**	**Patient perspectives**	**Main findings**
Toffa et al., (2020)	N/A	Review	Suggest FS diagnosis strategies to assist healthcare workers	FS	Review includes: • Homemade video • Induction test • Placebo • EEG • Prolactin level	N/A	N/A	Diagnosing FS requires knowledge of the relevant non-epileptic features.
Tolchin et al., (2020)	N/A	Review	Review motivational interviewing (MI) for FS	FS	N/A	Motivational interviewing	• Treatment barriers • Treatment adherence	Motivational interviewing is effective in improving psychotherapy adherence. Reasons for high treatment adherence includes loss of self-respect or independence, and the nature of the FS. Reasons for low treatment adherence includes patients' reluctance to acknowledge that the seizures are stress related; previous negative health care experiences and the care and attention received after FS.
Tsui et al., 2017)	N/A	Review	Provide an overview of evidence-based CD treatments	CD	N/A	Review includes: • CBT • Hypno-therapy • Physical rehabilitation	N/A	There is robust evidence for inpatient multidisciplinary treatment for CD. There is some evidence for hypnotherapy and

Author	**Country and setting**	**Study design**	**Study aims**	**Condition of interest**	**Diagnostic method**	**Treatment/ intervention**	**Patient perspectives**	**Main findings**
						• Inpatient multi-disciplinary treatment • Paradoxical intention treatment		CBT being effective interventions for CD.
Whitehead and Reuber, (2012)	N/A	Review	Provide an overview of vEEG research findings	FS	vEEG monitoring	N/A	N/A	An integrated multidisciplinary approach will assist in the differentiation between epilepsy and FS.
Widdess-Walsh et al., (2012)	N/A	Book chapter	Review the literature on the clinical management of FS	FS	Review includes: • vEEG • EEG • Home video recording • Serum prolactin assay • SPECT	Review includes: • Diagnostic explanation • Psycho-therapy • CBT • Family therapy • Biofeedback • Medication	N/A	Treatment should be individualised for each patient and focus on learning new coping skills. A combination of treatments may be the most beneficial for symptom reduction.
Williamson et al., (2014)	N/A	Book chapter	Provide an overview of the clinical management of FS	FS	Review includes: • MMPI/ MMPI-2 • PAI • vEEG	Review includes: • Medication • Diagnosis explanation • Psycho-therapy • CBT	Treatment adherence	Patients who initiated treatment were often more likely to continue to treatment completion than those who did not initiate treatment.

Author	Country and setting	Study design	Study aims	Condition of interest	Diagnostic method	Treatment/ intervention	Patient perspectives	Main findings
						• Psycho-education		
Zeuner et al., (2018)	N/A	Review	Provide an overview of the clinical and cognitive aspects of functional tremor	FND	Electrophysiology	N/A	N/A	Accelerometry is a useful diagnostic tool.

Appendix 5: Examples of recruitment invitations



ALLIANCE

An online survey exploring the experiences of the diagnosis and treatment processes for Functional Neurological Disorder (FND)

Type: **News Item**

Date Published: **31st January 2022**

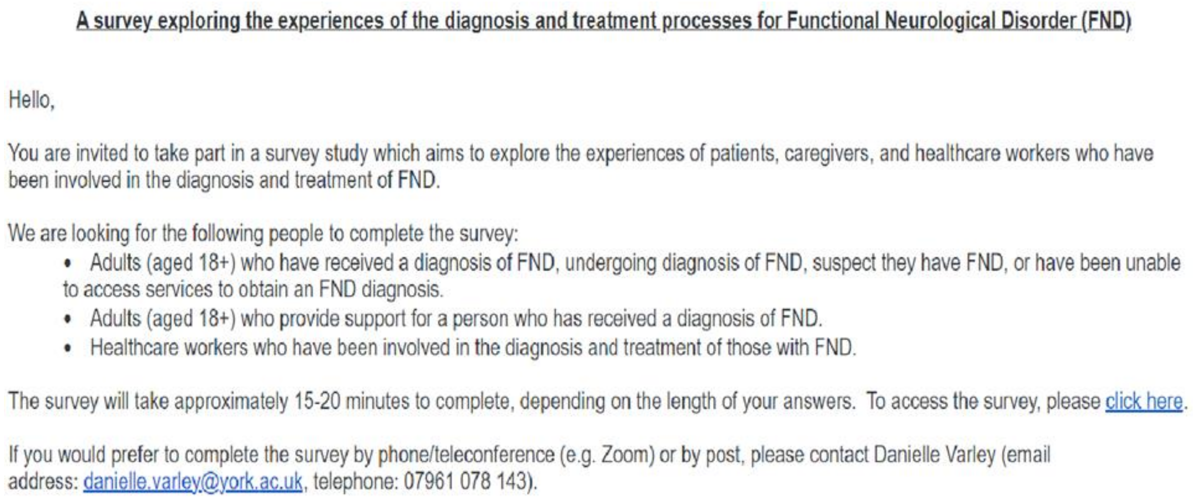
Participate in the University of York's survey.

This survey aims to explore the experiences of patients, caregivers, and healthcare workers involved in the clinical management of functional neurological disorder (FND). The hope is to gather these experiences to learn how to improve healthcare services for FND patients.

If you are a patient, caregiver, or healthcare worker based in the UK and has experience of the diagnostic and treatment processes for functional neurological disorder (FND), please consider taking 15-20 minutes to complete the survey. The survey has been granted ethical approval from the University of York and is completely confidential.

To access the survey, please click on the following link: **https://york.qualtrics.com/jfe/form/SV_egqkyD7FGTG2HUG (this link will take you away from our website)**

If you would prefer to complete the survey over the phone or by post, please email **danielle.varley@york.ac.uk** or text/call 07961 078 143.



A survey exploring the experiences of the diagnosis and treatment processes for Functional Neurological Disorder (FND)

Hello,

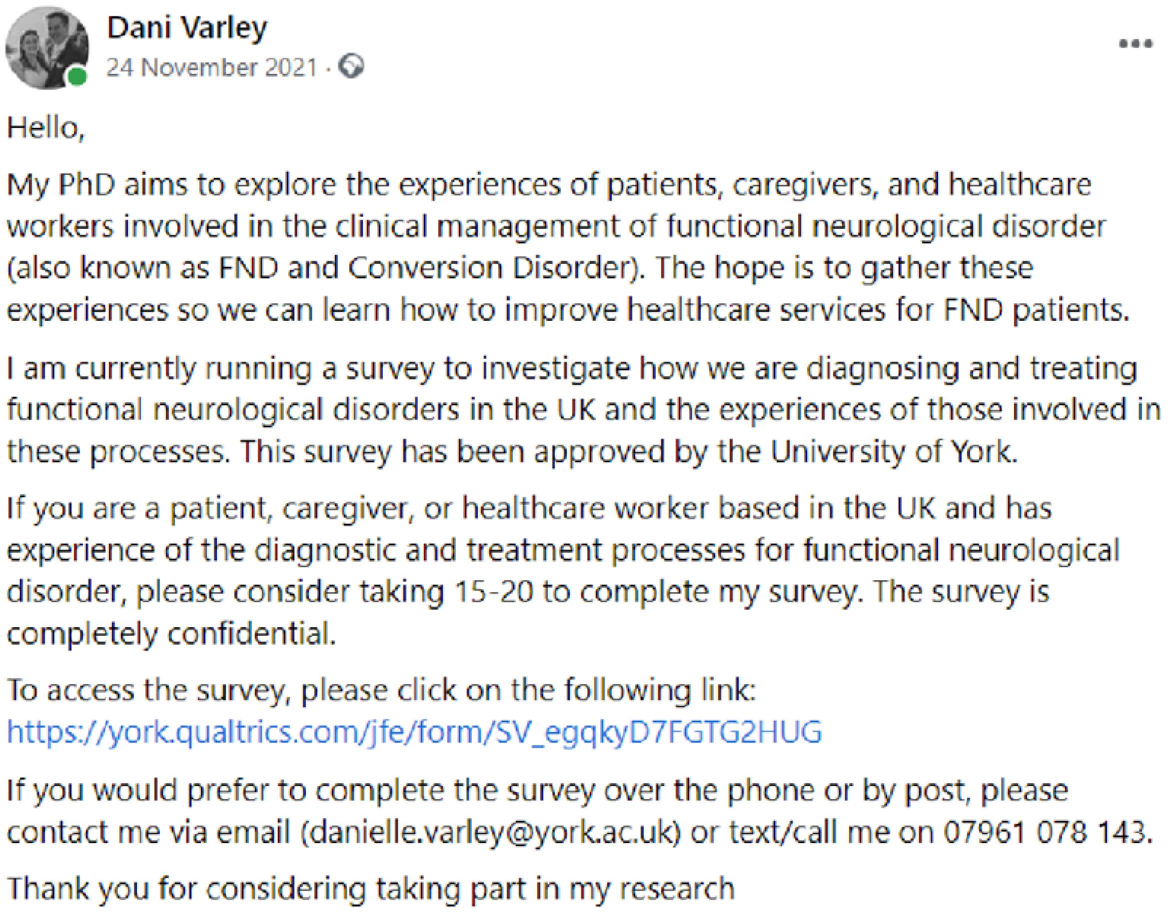
You are invited to take part in a survey study which aims to explore the experiences of patients, caregivers, and healthcare workers who have been involved in the diagnosis and treatment of FND.

We are looking for the following people to complete the survey:

- Adults (aged 18+) who have received a diagnosis of FND, undergoing diagnosis of FND, suspect they have FND, or have been unable to access services to obtain an FND diagnosis.
- Adults (aged 18+) who provide support for a person who has received a diagnosis of FND.
- Healthcare workers who have been involved in the diagnosis and treatment of those with FND.

The survey will take approximately 15-20 minutes to complete, depending on the length of your answers. To access the survey, please click here.

If you would prefer to complete the survey by phone/teleconference (e.g. Zoom) or by post, please contact Danielle Varley (email address: danielle.varley@york.ac.uk, telephone: 07961 078 143).



Dani Varley

24 November 2021 ·

Hello,

My PhD aims to explore the experiences of patients, caregivers, and healthcare workers involved in the clinical management of functional neurological disorder (also known as FND and Conversion Disorder). The hope is to gather these experiences so we can learn how to improve healthcare services for FND patients.

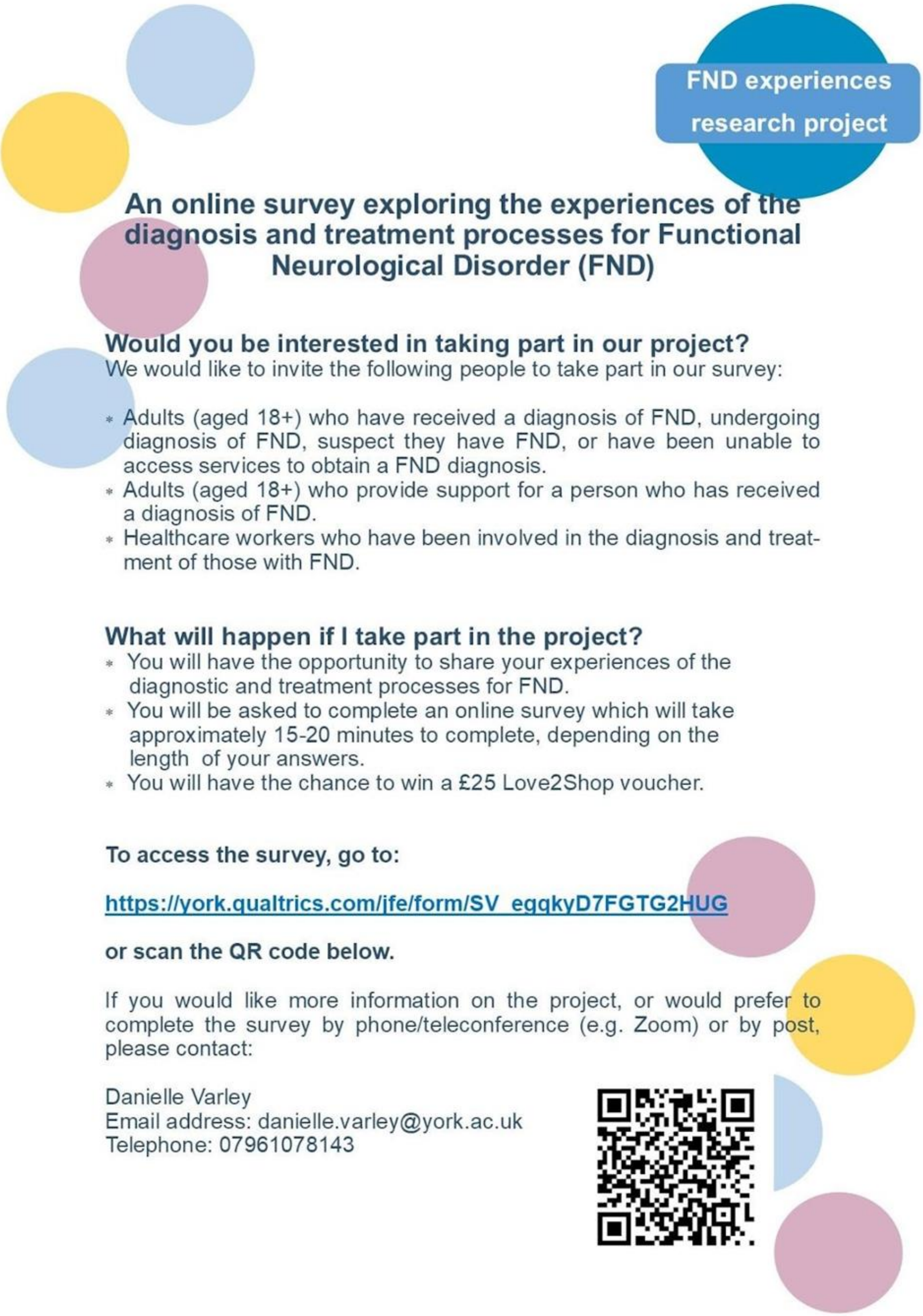
I am currently running a survey to investigate how we are diagnosing and treating functional neurological disorders in the UK and the experiences of those involved in these processes. This survey has been approved by the University of York.

If you are a patient, caregiver, or healthcare worker based in the UK and has experience of the diagnostic and treatment processes for functional neurological disorder, please consider taking 15-20 to complete my survey. The survey is completely confidential.

To access the survey, please click on the following link: https://york.qualtrics.com/jfe/form/SV_egqkyD7FGTG2HUG

If you would prefer to complete the survey over the phone or by post, please contact me via email (danielle.varley@york.ac.uk) or text/call me on 07961 078 143.

Thank you for considering taking part in my research



FND experiences research project

An online survey exploring the experiences of the diagnosis and treatment processes for Functional Neurological Disorder (FND)

Would you be interested in taking part in our project?

We would like to invite the following people to take part in our survey:

- Adults (aged 18+) who have received a diagnosis of FND, undergoing diagnosis of FND, suspect they have FND, or have been unable to access services to obtain a FND diagnosis.
- Adults (aged 18+) who provide support for a person who has received a diagnosis of FND.
- Healthcare workers who have been involved in the diagnosis and treatment of those with FND.

What will happen if I take part in the project?

- You will have the opportunity to share your experiences of the diagnostic and treatment processes for FND.
- You will be asked to complete an online survey which will take approximately 15-20 minutes to complete, depending on the length of your answers.
- You will have the chance to win a £25 Love2Shop voucher.

To access the survey, go to:

https://york.qualtrics.com/jfe/form/SV_egqkyD7FGTG2HUG

or scan the QR code below.

If you would like more information on the project, or would prefer to complete the survey by phone/teleconference (e.g. Zoom) or by post, please contact:

Danielle Varley
Email address: danielle.varley@york.ac.uk
Telephone: 07961078143

Appendix 6: Survey questions for each population group

Demographic questions completed by all participants

1. Do you identify as:
   - ☐ Female
   - ☐ Male
   - ☐ Non-binary
   - ☐ Other (please specify below)
   - ☐ Prefer not to answer

2. What is your age?
   - ☐ Under 18
   - ☐ 18 - 24
   - ☐ 25 - 34
   - ☐ 35 - 44
   - ☐ 45 - 54
   - ☐ 55 - 64
   - ☐ 65 - 74
   - ☐ 75 - 84
   - ☐ 85 or older
   - ☐ Prefer not to answer

3. What is your ethnic group? *Please choose the option that best describes your ethnic group or background*

   - ☐ White
     - ○ Scottish/English/Welsh/Northern Irish/British
     - ○ Irish
     - ○ Gypsy or Irish Traveller
     - ○ Any other White background, please describe
   - ☐ Mixed/Multiple ethnic groups
     - ○ White and Black Caribbean
     - ○ White and Black African
     - ○ White and Asian
     - ○ Any other Mixed/Multiple ethnic background, please describe
   - ☐ Asian/Asian British
     - ○ Indian
     - ○ Pakistani
     - ○ Bangladeshi
     - ○ Chinese
     - ○ Any other Asian background, please describe
   - ☐ Black/African/Caribbean/Black British
     - ○ African
     - ○ Caribbean
     - ○ Any other Black/African/Caribbean background, please describe
   - ☐ Other ethnic group
     - ○ Arab
     - ○ Any other ethnic group, please describe [free text box]

☐ Prefer not to answer

4. Which region do you live in?

☐ England:

  - ○ North East
  - ○ North West
  - ○ Yorkshire and the Humber
  - ○ East Midlands
  - ○ West Midlands
  - ○ East of England
  - ○ London
  - ○ South East
  - ○ South West

☐ Wales:

  - ○ North Wales
  - ○ Mid-Wales
  - ○ South Wales

☐ Scotland:

  - ○ Borders
  - ○ Dumfries and Galloway
  - ○ Strathclyde
  - ○ Lothian
  - ○ Central
  - ○ Grampian
  - ○ Highlands and Islands

☐ Northern Ireland

  - ○ Antrim
  - ○ Armagh
  - ○ Down
  - ○ Fermanagh
  - ○ Londonderry
  - ○ Tyrone

5. Have you achieved a qualification at degree level or above? (e.g. degree, foundation degree, HND or HNC, NVQ level 4 and above, teaching or nursing)

☐ Yes
☐ No

6. Have you achieved any other qualifications? *Please tick all that apply*

☐ 5 or more GCSEs (A*-C, 9-4), O levels (passes) or CSEs (grade 1)
☐ Any other GCSEs, O levels or CSEs (any grades) or Basic Skills course
☐ 2 or more A levels, 4 or more AS levels
☐ 1 A level, 2-3 AS levels
☐ 1 AS level
☐ NVQ level 3, BTEC National, OND or ONC, City and Guilds Advanced Craft
☐ NVQ level 2, BTEC General, City and Guilds Craft
☐ NVQ level 1
☐ Any other qualifications, equivalent unknown
☐ No qualifications

7. What is your work status?
    - ☐ Working as an employee (this includes casual or temporary work, part and full time work)
    - ☐ Self-employed or freelance with employees
    - ☐ Self-employed or freelance without employees
    - ☐ Student
    - ☐ Retired
    - ☐ Looking after home or family (e.g., stay at home parent, carer)
    - ☐ Temporarily away from work ill
    - ☐ Other (please specify below) [free text box]
    - ☐ Prefer not to answer

8. In your main job, how many hours a week do you usually work?
    - ☐ 0-15
    - ☐ 16-30
    - ☐ 31-48
    - ☐ 49 or more
    - ☐ Prefer not to answer

9. Have you completed an apprenticeship (e,g, trade, advanced, foundation, modern?) [patients and caregivers only]
    - ☐ Yes
    - ☐ No

10. What is/was your full job title? *(for example, primary school teacher, catering assistant, retail worker) If you are a student, please type in 'student'* [patients and caregivers only]

    [free text box]

11. What is/was the main activity of your organisation, business or freelance work? *e.g., clothing retail, general hospital, primary education. If you are a student, please type in 'education'* [patients and caregivers only]

    [free text box]

<u>Healthcare worker specific questions</u>

Section 1: Demographic/general questions

1. What is your job title and occupational group (for example, physiotherapist – therapy professional or nurse – nursing and midwifery professional)?

    [free text box]

2. How many years have you been in practice?
   - ☐ 0-5
   - ☐ 6-10
   - ☐ 11-15
   - ☐ 16-20
   - ☐ 20 or more
   - ☐ Prefer not to answer

3. In which service type do you work?

   [free text box]

4. How many years have you been working with patients with FND/CD?
   - ☐ 0-5
   - ☐ 6-10
   - ☐ 11-15
   - ☐ 16-20
   - ☐ 20 or more
   - ☐ Prefer not to answer

5. How many FND/CD patients do you personally see in your service per year?
   - ☐ 0-5
   - ☐ 6-10
   - ☐ 11-20
   - ☐ 21-30
   - ☐ 31-40
   - ☐ 41-50
   - ☐ 50 or more
   - ☐ Prefer not to answer

6. How would you rate your knowledge/expertise of FND/CD?
   - ☐ No knowledge/expertise
   - ☐ Some knowledge/expertise
   - ☐ Moderate knowledge/expertise
   - ☐ Very knowledgeable/expertise
   - ☐ Prefer not to answer

7. Please describe below the training/education you have received about FND/CD

   [free text box]

8. Do you feel that you have received sufficient training about FND/CD as part of your clinical training?

   - ☐ Yes
   - ☐ No - why? Please specify below

   [free text box]

Section 2: Diagnostic methods questions

1. Does your service provide diagnostic tests or treatment(s) for those with FND/CD?
   - ☐ Yes
   - ☐ No
   - ☐ Prefer not to answer

2. Have you previously worked in a service which provided diagnostic tests or treatment(s) for those with FND/CD?
   - ☐ Yes
   - ☐ No

3. If applicable, which assessments have you used, or helped with, in the past two years to diagnose (or assist in diagnosing) a patient with FND/CD:
   - ☐ Biomarkers
   - ☐ Blood sample
   - ☐ Computed Tomography (CT) scan
   - ☐ EKG monitoring
   - ☐ Electroencephalogram (EEG)
   - ☐ Electromyography (EMG) / Nerve Conduction Tests
   - ☐ Eye-witness reports of seizure semiology
   - ☐ Functional Magnetic Resonance Imaging (fMRI) Scan
   - ☐ Magnetic Resonance Imaging (MRI) Scan
   - ☐ Neurological exam(s)
   - ☐ Neurophysiological assays
   - ☐ Positive signs (e.g. Hoover's sign, drift without pronation)
   - ☐ Positron emission tomography (PET)
   - ☐ Provocative testing (e.g. verbal suggestion, body part compression)
   - ☐ Psychiatric Assessment/Evaluation
   - ☐ Salivary cortisol
   - ☐ Serum levels
   - ☐ vEEG scan
   - ☐ Video-electroencephalographic monitoring (VEM)
   - ☐ Other (please specify) [free text box]
   - ☐ Not applicable
   - ☐ Prefer not to answer

4. Approximately, how many patients being assessed for FND/CD have you provided the selected assessment(s) to

   [free text box]

5. What training and supervision have you receive(d) to deliver the assessment(s)?

   [free text box]

6. Where, when and how is/are the assessment(s) conducted?

   [free text box]

7. Which assessments do you think are necessary in order to diagnose (or assist in diagnosing) a patient with FND/CD? *Please select all that apply*

- ☐ Biomarkers
- ☐ Blood sample
- ☐ Computed Tomography (CT) scan
- ☐ EKG monitoring
- ☐ Electroencephalogram (EEG)
- ☐ Electromyography (EMG) / Nerve Conduction Tests
- ☐ Eye-witness reports of seizure semiology
- ☐ Functional Magnetic Resonance Imaging (fMRI) Scan
- ☐ Magnetic Resonance Imaging (MRI) Scan
- ☐ Neurological exam(s)
- ☐ Neurophysiological assays
- ☐ Positive signs (e.g. Hoover's sign, drift without pronation)
- ☐ Positron emission tomography (PET)
- ☐ Provocative testing (e.g. verbal suggestion, body part compression)
- ☐ Psychiatric Assessment/Evaluation
- ☐ Salivary cortisol
- ☐ Serum levels
- ☐ vEEG scan
- ☐ Video-electroencephalographic monitoring (VEM)
- ☐ Other (please specify) [free text box]
- ☐ Not applicable
- ☐ Prefer not to answer

8. If applicable, what is the average duration from time of referral to diagnosis in your service for a patient receiving test(s) to assess for FND/CD?
   - ☐ 0-6 months
   - ☐ 7-12 months
   - ☐ 13-18 months
   - ☐ 19-24 months
   - ☐ 25-30 months
   - ☐ 31-36 months
   - ☐ 37+ months
   - ☐ Not applicable
   - ☐ Prefer not to answer

9. Does your service provide support to FND/CD patients and their caregivers during the diagnostic process? (such as sign posting to support groups)
   - ☐ Yes - what support does your service provide? [free text box]
   - ☐ No

10. Do you think the process your service uses for diagnosing a patient with CD/FND is suitable?
    - ☐ Yes - why is this? [free text box]
    - ☐ No - how could the process be improved? [free text box]

Section 3: Treatment/intervention questions

1. If applicable, what treatment options does your service provide for patients diagnosed with FND/CD? *Please select all that apply*
   - ☐ Adjunctive physical activity (APA)
   - ☐ Biofeedback
   - ☐ Chronic pain rehabilitation program
   - ☐ Cognitive behavioural therapy (CBT)
   - ☐ Complementary/Alternative medicine - please specify
   - ☐ Dialectical behavioural therapy (DBT)
   - ☐ Educational website
   - ☐ EMDR
   - ☐ Exposure therapy
   - ☐ Family therapy
   - ☐ Hypnosis/Hypnotherapy
   - ☐ Medication (including antidepressants)
   - ☐ Mindfulness based therapy
   - ☐ Motivational interviewing
   - ☐ Non-invasive brain stimulation
   - ☐ Occupational Therapy
   - ☐ Physiotherapy/Physical rehabilitation
   - ☐ Psychodynamic therapy
   - ☐ Psychoeducation
   - ☐ Psychotherapy
   - ☐ Repetitive transcranial magnetic stimulation (rTMS/TMS)
   - ☐ Scripted diagnosis/Diagnostic explanation
   - ☐ Virtual reality delivered mirror visual feedback (VR-MVF)
   - ☐ Other - please specify [free text box]
   - ☐ Don’t know
   - ☐ Not applicable
   - ☐ Prefer not to answer

2. Do you think the treatment(s)/intervention(s) offered by your service for patients with FND/CD are effective?
   - ☐ Yes
   - ☐ No - please explain why
   - ☐ Not applicable
   - ☐ Prefer not to answer

3. What intervention(s) do you think should be used in the treatment of FND/CD? *Please select all that apply*
   - ☐ Adjunctive physical activity (APA)
   - ☐ Biofeedback
   - ☐ Chronic pain rehabilitation program
   - ☐ Cognitive behavioural therapy (CBT)
   - ☐ Complementary/Alternative medicine - please specify
   - ☐ Dialectical behavioural therapy (DBT)
   - ☐ Educational website
   - ☐ EMDR
   - ☐ Exposure therapy
   - ☐ Family therapy
   - ☐ Hypnosis/Hypnotherapy

☐ Medication (including antidepressants)
☐ Mindfulness based therapy
☐ Motivational interviewing
☐ Non-invasive brain stimulation
☐ Occupational Therapy
☐ Physiotherapy/Physical rehabilitation
☐ Psychodynamic therapy
☐ Psychoeducation
☐ Psychotherapy
☐ Repetitive transcranial magnetic stimulation (rTMS/TMS)
☐ Scripted diagnosis/Diagnostic explanation
☐ Virtual reality delivered mirror visual feedback (VR-MVF)
☐ Other - please specify [free text box]
☐ Don’t know
☐ Not applicable
☐ Prefer not to answer

4. Which healthcare workers should be involved in the diagnosis and/or treatment of FND/CD? *Please select all that apply*

☐ Counsellors
☐ General Practitioners
☐ Neurologists
☐ Nurses
☐ Occupational Therapists
☐ Physical therapist/ physiotherapists
☐ Psychiatrists
☐ Psychologists
☐ Other - please specify [free text box]

5. Do you feel that your service involves patients and caregivers in deciding what type of support or treatment the patient receives for their FND/CD diagnosis?

☐ Yes - please provide details on how your service involves patients and caregivers in their support/treatment [free text box]
☐ No – how would you involve patients and their caregivers in their CD/FND treatment? [free text box]
☐ Not applicable
☐ Prefer not to answer

6. Do you feel that new approaches or treatments need to be implemented into services to support patients (alongside caregivers and healthcare workers) with FND/CD

☐ Yes - please describe why [free text box]
☐ No- please describe why [free text box]

7. Please describe below any thoughts or experiences you would like to share regarding working with patients with FND/CD:

[free text box]

Patient specific survey questions

Section 1: Demographic/General questions

1. Which kinds of income do you personally receive?
   - ☐ Child benefit
   - ☐ Earnings from employment (including income from government training scheme)
   - ☐ Earnings from self-employment
   - ☐ Income from rent
   - ☐ Income Support
   - ☐ Interest from investments
   - ☐ Interest from savings
   - ☐ Pension from former employer
   - ☐ Personal Pension
   - ☐ State Pension
   - ☐ Tax Credits
   - ☐ Universal Credit
   - ☐ Other sources (e.g., other private income sources; student loan, second job) [free text box]
   - ☐ Other kinds of regular allowance from outside the household
   - ☐ Other state benefits (any state benefit or allowance excluding housing benefit, local housing allowance, council tax benefit/support or the Universal credit amount allowed for rent)
   - ☐ Not applicable

2. Do you own or rent your current residence? *For the purpose of the survey, you own your home even if you have an outstanding mortgage loan*
   - ☐ Own
   - ☐ Privately rent
   - ☐ Council rent
   - ☐ Living in parents property/property owned by other family members
   - ☐ Other - please specify [free text box]

3. Who do you live with?
   - ☐ I live alone
   - ☐ With spouse/partner
   - ☐ With family
   - ☐ I live in residential accommodation
   - ☐ Other - please specify [free text box]
   - ☐ Prefer not to say

4. Do you live in a...
   - ☐ Rural area
   - ☐ Suburban area
   - ☐ Urban area

5. Have you received a diagnosis of any of the following conditions:
   - ☐ Conversion disorder (CD)
   - ☐ Functional neurological symptom disorder
   - ☐ Functional neurological disorder (FND)
   - ☐ Functional movement disorder
   - ☐ Dissociative neurological disorder
   - ☐ Functional seizures (such as psychogenic seizures, non-epileptic seizures and non-epileptic attacks [also known as NEAD or PNES])
   - ☐ No
   - ☐ I am currently accessing services to receive an FND or similar diagnosis
   - ☐ I have been unable to access services to receive an FND or similar diagnosis - *why were you unable to access services to receive an FND diagnosis?* [free text box]
   - ☐ Don’t know
   - ☐ Prefer not to answer

6. Have you been diagnosed with any other medical condition?
   - ☐ Yes - *please specify* [free text box]
   - ☐ No
   - ☐ Prefer not to say

7. What symptoms do you experience?
   - ☐ Deafness or hearing difficulties
   - ☐ Difficult swallowing
   - ☐ Difficulty concentrating
   - ☐ Dizziness or loss of balance
   - ☐ Fatigue
   - ☐ Heart palpitations and/or fainting
   - ☐ Loss of the senses (e.g., smell)
   - ☐ Memory problems
   - ☐ Numbness
   - ☐ Pain
   - ☐ Paralysis
   - ☐ Seizures or sudden loss of awareness
   - ☐ Speech problems
   - ☐ Stomach or bowel problems
   - ☐ Symptoms causing problems with movement (such as tremors or twitches, shakes and weakness)
   - ☐ Tingling sensations in the skin
   - ☐ Unexplained blackouts
   - ☐ Vision problems
   - ☐ Other - *please specify* [free text box]

Section 2: Diagnostic questions

1. When were you diagnosed with functional neurological disorder/conversion disorder)? If you do not know the exact date, please put the year of diagnosis.
   If you have not yet been diagnosed with FND/CD, please write 'not applicable’

   [free text box]

2. Do you agree with your FND/CD diagnosis?
   - ☐ Yes
   - ☐ No - *why do you not agree with your diagnosis?* [free text box]
   - ☐ Not applicable
   - ☐ Prefer not to say

3. Do you think any of the following are related to your FND/CD symptoms and diagnosis? *Please tick all that apply*
   - ☐ Adverse Childhood Experiences (childhood trauma)
   - ☐ Being involved in an accident
   - ☐ Being physically unwell
   - ☐ Bereavement
   - ☐ Chronic fatigue syndrome (CFS/ME)
   - ☐ Inflammation/Chronic inflammation
   - ☐ Headaches/migraines
   - ☐ Head trauma/ brain injury
   - ☐ Mental health condition(s) (such as anxiety, depression, obsessive-compulsive disorder)
   - ☐ Pain/chronic pain
   - ☐ Post-traumatic stress disorder (PTSD)
   - ☐ Stress (including chronic stress)
   - ☐ Stroke
   - ☐ Suffering from an infection/infectious disease
   - ☐ Surgical operation(s)
   - ☐ Other - *please specify* [free text box]
   - ☐ Don’t know
   - ☐ No
   - ☐ Prefer not to answer

4. Which healthcare workers were involved when you were undergoing diagnostic tests?
   - ☐ A&E doctor
   - ☐ GP
   - ☐ Neurologist
   - ☐ Nurse
   - ☐ Paediatrician
   - ☐ Psychiatrist
   - ☐ Psychologist
   - ☐ Other - *please specify* [free text box]
   - ☐ Don’t know
   - ☐ Not applicable
   - ☐ Prefer not to answer

5. Which services did you visit when you were undergoing the FND/CD diagnostic tests?
   - ☐ Accident and Emergency (A&E)/Emergency Room (ER)
   - ☐ Epilepsy unit/ward
   - ☐ General Practitioners (GP) office

- ☐ Neurology centre/ward
- ☐ Paediatrics/children’s ward
- ☐ Psychology/Psychiatric services
- ☐ Phlebotomy/blood taking unit
- ☐ Stroke unit/ward
- ☐ Other - *please specify* [free text box]
- ☐ I did not attend any services
- ☐ Don’t know
- ☐ Prefer not to answer

6. How did you feel accessing these services?

   [free text box]

7. Did you feel that you needed to access these service(s)?
   - ☐ Yes
   - ☐ No - *why is this?* [free text box]

8. Please describe below your experiences when accessing healthcare service(s) for your FND/CD symptoms/diagnosis:

   [free text box]

9. Which medical professional(s) gave you your FND/CD diagnosis?
   - ☐ A&E doctor
   - ☐ GP
   - ☐ Neurologist
   - ☐ Nurse
   - ☐ Paediatrician
   - ☐ Psychiatrist
   - ☐ Psychologist
   - ☐ Other - *please specify* [free text box]
   - ☐ Don’t know
   - ☐ Not applicable
   - ☐ Prefer not to answer

10. Do you feel that the medical professional(s) who gave you your FND/CD diagnosis gave you enough information about the condition *(e.g., what could cause the condition, treatments etc)*
    - ☐ Yes
    - ☐ No - *why is this?* [free text box]
    - ☐ Not applicable

11. How long did it take for you to receive your diagnosis from when you first reported symptoms to a healthcare worker *(e.g., a GP or an A&E doctor)?*

- ☐ 0-6 months
- ☐ 6-12 months
- ☐ 1-2 years
- ☐ 2-5 years
- ☐ Over 5 years
- ☐ Not applicable
- ☐ Don't know
- ☐ Prefer not to answer

12. What test(s) were used to help diagnose you with FND/CD? *Please select all that apply*

- ☐ Biomarkers
- ☐ Blood sample
- ☐ Computed Tomography (CT) scan
- ☐ EKG monitoring
- ☐ Electroencephalogram (EEG)
- ☐ Electromyography (EMG) / Nerve Conduction Tests
- ☐ Eye-witness reports of seizure semiology
- ☐ Functional Magnetic Resonance Imaging (fMRI) Scan
- ☐ Magnetic Resonance Imaging (MRI) Scan
- ☐ Neurological exam(s)
- ☐ Neurophysiological assays
- ☐ Positive signs (e.g. Hoover's sign, drift without pronation)
- ☐ Positron emission tomography (PET)
- ☐ Provocative testing (e.g. verbal suggestion, body part compression)
- ☐ Psychiatric Assessment/Evaluation
- ☐ Salivary cortisol test (spit test)
- ☐ Serum levels
- ☐ vEEG scan
- ☐ Video-electroencephalographic monitoring (VEM)
- ☐ Other - *please specify* [free text box]
- ☐ Not applicable
- ☐ Prefer not to answer

13. Thinking back to when you were undergoing tests to receive your FND/CD diagnosis, is there anything the services who saw you should have done differently?

- ☐ Yes - *please specify* [free text box]
- ☐ No
- ☐ Not applicable
- ☐ Prefer not to say

14. Did you access any support during your FND/CD diagnosis assessment(s)? *Please select all that apply*
- ☐ Attended a patient support group(s)/online forums
- ☐ Support from family or friends
- ☐ Social services support
- ☐ Support from charities/organisations
- ☐ I did not access any support
- ☐ Other - *please specify* [free text box]
- ☐ Not applicable
- ☐ Prefer not to answer

15. What support would you have liked to receive when you were undergoing tests to receive your FND/CD diagnosis?

[free text box]

16. Thinking back to when you were undergoing diagnostic tests (such as a blood test, or an EEG test), and when you received your FND/CD diagnosis, do you feel that the medical professionals involved were supportive of you and your condition?
- ☐ Yes - *please specify* [free text box]
- ☐ No - *please specify* [free text box]
- ☐ Not applicable
- ☐ Prefer not to answer

Section 3: Treatment/intervention questions

1. What treatments are you receiving (or received) since your FND/CD diagnosis to help you with your symptoms? *Please select all that apply*
- ☐ Adjunctive physical activity (APA)
- ☐ Biofeedback (a mind-body technique that involves teaching people how to recognise the physical signs of anxiety and stress [such as increased heart rate])
- ☐ Chronic pain rehabilitation program
- ☐ Cognitive behavioural therapy (CBT)
- ☐ Complementary/Alternative medicine - please specify
- ☐ Dialectical behavioural therapy (DBT)
- ☐ Educational website
- ☐ EMDR
- ☐ Exposure therapy
- ☐ Family therapy
- ☐ Hypnosis/Hypnotherapy
- ☐ Medication (including antidepressants)
- ☐ Mindfulness based therapy
- ☐ Motivational interviewing
- ☐ Non-invasive brain stimulation
- ☐ Occupational Therapy
- ☐ Physiotherapy/Physical rehabilitation
- ☐ Psychodynamic therapy
- ☐ Psychoeducation

- ☐ Psychotherapy
- ☐ Repetitive transcranial magnetic stimulation (rTMS/TMS)
- ☐ Scripted diagnosis/Diagnostic explanation
- ☐ Virtual reality delivered mirror visual feedback (VR-MVF)
- ☐ Other - *please specify* [free text box]
- ☐ I have not undergone any treatments for my FND/CD symptoms since receiving my diagnosis
- ☐ Don’t know
- ☐ Not applicable
- ☐ Prefer not to answer

2. Have the treatments you received been easy to follow?

   [free text box]

3. How long have you been undergoing these treatment(s)? *Please list the duration for all treatments you have received below*

   [free text box]

4. If you are no longer accessing these treatment(s), how long did they last? *Please answer using months*

   [free text box]

5. Do you feel that these treatments worked or helped reduce your FND/CD symptoms?
   - ☐ Yes - why? *Please specify* [free text box]
   - ☐ No - why? *Please specify* [free text box]
   - ☐ Prefer not to say

6. Do you feel that the healthcare workers (such as your doctor) involved you and your family/caregiver (if applicable) when deciding the type of support or treatment(s) you receive(d)?
   - ☐ Yes – how did they involve you and your family/caregiver? *please specify* [free text box]
   - ☐ No - *please specify why* [free text box]
   - ☐ Prefer not to say

7. Is there anything else you would like to share with us about your experience of being diagnosed and/or treated for conversion disorder/functional neurological disorder?

   [free text box]

Caregiver specific questions

Section 1: Demographic/general questions

1. What is your relationship with the person you provide care for?
   - ☐ Spouse/ Partner
   - ☐ Child/child-in-law
   - ☐ Parent/Parent-in-law/Guardian
   - ☐ Grandparent/grandparent-in-law
   - ☐ Other family member – *please specify* [free text box]
   - ☐ Friend/neighbour
   - ☐ Other – *please specify* [free text box]
   - ☐ Prefer not to answer

2. Has the person you provide support for received a functional neurological disorder/conversion disorder (FND/CD) diagnosis?
   - ☐ Yes
   - ☐ They are currently accessing services to receive an FND/CD diagnosis
   - ☐ They have been unable to access services to receive an FND/CD diagnosis
   - ☐ No
   - ☐ Prefer not to answer

3. What type of FND/CD do they have? *Please select from the list below*:
   - ☐ Conversion disorder (CD)
   - ☐ Functional neurological symptom disorder
   - ☐ Functional neurological disorder (FND)
   - ☐ Functional movement disorder
   - ☐ Dissociative neurological disorder
   - ☐ Functional seizures (including psychogenic seizures, non-epileptic seizures and non-epileptic attacks [also known as PNES or NEAD)
   - ☐ Don’t know
   - ☐ Prefer not to answer

4. For how long have you provided support to the person with FND/CD?
   - ☐ 0-6 months
   - ☐ 6-12 months
   - ☐ 1-2 years
   - ☐ 2-5 years
   - ☐ Over 5 years
   - ☐ Prefer not to answer

5. On average, how many hours per week do you spend in your caregiver role? *Please exclude anything you do as part of your paid employment*
   - ☐ 0-9 hours a week
   - ☐ 10-19 hours a week
   - ☐ 20-34 hours a week
   - ☐ 35-49 hours per week
   - ☐ 50 or more hours a week
   - ☐ Prefer not to answer

6. Do you have any medical conditions?
   - ☐ Yes - please specify [free text box]
   - ☐ No
   - ☐ Prefer not to answer

7. What type of support do you provide? *Please select all that apply*
   - ☐ Assisting with household tasks/ personal errands
   - ☐ Assisting with personal care (for example, showering)
   - ☐ Providing transport to appointments or social visits
   - ☐ Emotional support
   - ☐ Financial support
   - ☐ Social companionship
   - ☐ Arranging or assisting with professional care
   - ☐ Assisting with medical treatments
   - ☐ Other - please specify [free text box]
   - ☐ Prefer not to answer

8. Do you feel you are doing what you can to help the person you provide support for with their condition?
   - ☐ Yes
   - ☐ No
   - ☐ Prefer not to answer

9. Do you ever feel overwhelmed as a caregiver, or that the person you support is a burden?
   - ☐ Yes
   - ☐ No
   - ☐ Prefer not to answer

10. Has being a caregiver had a negative impact on your daily life *(e.g. financially, emotionally)?*
    - ☐ Yes - *If so, please specify why* [free text box]
    - ☐ No
    - ☐ Prefer not to answer

11. Do you feel that the person you provide support for is satisfied with the type of support you provide?
    - ☐ Yes
    - ☐ No
    - ☐ Prefer not to answer

12. Do you feel that you need professional support to help the person you are providing care for?
    - ☐ Yes
    - ☐ No
    - ☐ Prefer not to answer

13. Do you feel that you have enough time to look after yourself as well as the person you support?
    - ☐ Yes
    - ☐ No
    - ☐ Prefer not to answer

14. Have you received any of the following support while being a caregiver *(e.g., attending a caregiver's support group, support from family or friends)?*
    - ☐ Attending a carer's support group(s)
    - ☐ Carer Information and training
    - ☐ Carer's allowance or other benefits
    - ☐ Respite care
    - ☐ Social work support
    - ☐ Support from family or friends
    - ☐ Other - *please specify* [free text box]
    - ☐ I have not received any support
    - ☐ Prefer not to answer

Section 2: Diagnostic questions

1. When did the person you provide support for receive their FND/CD diagnosis? *(if you do not remember the exact date, please put the year of diagnosis)*

   [free text box]

2. What test(s) were used to help diagnose the person you provide support with FND/CD? *Please select all that apply*
   - ☐ Biomarkers
   - ☐ Blood sample
   - ☐ Computed Tomography (CT) scan
   - ☐ EKG monitoring
   - ☐ Electroencephalogram (EEG)

☐ Electromyography (EMG) / Nerve Conduction Tests
☐ Eye-witness reports of seizure semiology
☐ Functional Magnetic Resonance Imaging (fMRI) Scan
☐ Magnetic Resonance Imaging (MRI) Scan
☐ Neurological exam(s)
☐ Neurophysiological assays
☐ Positive signs (e.g. Hoover's sign, drift without pronation)
☐ Positron emission tomography (PET)
☐ Provocative testing (e.g. verbal suggestion, body part compression)
☐ Psychiatric Assessment/Evaluation
☐ Salivary cortisol test (spit test)
☐ Serum levels
☐ vEEG scan
☐ Video-electroencephalographic monitoring (VEM)
☐ Other - *please specify* [free text box]
☐ Not applicable
☐ Prefer not to answer

3. Thinking back to when the person you care for received their FND/CD diagnosis, do you feel that the healthcare worker(s) were supportive of you and the person you provide support for?

☐ Yes
☐ No – *please specify* [free text box]
☐ Not applicable
☐ Prefer not to answer

4. Thinking back to when the person you care for was undergoing diagnostic tests, is there anything you feel that the services could have done differently?

   [free text box]

Section 3: treatments/intervention questions

1. Has the person you provide support for received any of the following treatments for their FND/CD diagnosis? *Please select all that apply*
   ☐ Adjunctive physical activity (APA)
   ☐ Biofeedback
   ☐ Chronic pain rehabilitation program
   ☐ Cognitive behavioural therapy (CBT)
   ☐ Complementary/Alternative medicine - *please specify* [free text box]
   ☐ Dialectical behavioural therapy (DBT)
   ☐ Educational website
   ☐ EMDR
   ☐ Exposure therapy
   ☐ Family therapy
   ☐ Hypnosis/Hypnotherapy
   ☐ Medication (including antidepressants)

☐ Mindfulness based therapy
☐ Motivational interviewing
☐ Non-invasive brain stimulation
☐ Occupational Therapy
☐ Physiotherapy/Physical rehabilitation
☐ Psychodynamic therapy
☐ Psychoeducation
☐ Psychotherapy
☐ Repetitive transcranial magnetic stimulation (rTMS/TMS)
☐ Scripted diagnosis/Diagnostic explanation
☐ Virtual reality delivered mirror visual feedback (VR-MVF)
☐ Other - *please specify* [free text box]
☐ Don’t know
☐ Not applicable
☐ Prefer not to answer

2. Do you feel that the healthcare workers (e.g. nurses, doctors) involved you and the person you provide support for in deciding the type of support or treatment to be put in place?

☐ Yes - *Please specify* [free text box]
☐ No
☐ Not applicable
☐ Prefer not to answer

3. Is there anything else you would like to share with us about your experience of the diagnosis and/or treatment for conversion disorder/functional neurological disorder?

[free text box]

Appendix 7: Content analysis coding list

Theme	Theme description	Code	Subcode	Subcode description
The impact of communication and information sharing	The impact of communication on patients was profound. Patient and caregiver comments were predominantly negative in nature, with some facing negative attitudes and unprofessional behaviours from healthcare workers when accessing services. Patient-healthcare worker relationships were unable to develop due to the lack of effective communication and information being rovided to patients and caregivers.	Professional behaviour when communicating with patients and caregivers	Communication, attitudes, and behaviour	Communication was a major focal point throughout survey responses. Some patients found support from compassionate and empathetic healthcare workers. Patients reported how healthcare workers behaved towards them, with some experiencing severe and even harmful behaviour. Patients faced verbal and physical abuse by a minority of healthcare workers.
			Malingering and stigma	While there were many instances of good communication and professional behaviour experienced by patients, some received accusations of malingering and stigma.

Theme	Theme description	Code	Subcode	Subcode description
			Impact of negative comments/behaviours from healthcare workers	Experiences of negative comments, behaviours and attitudes had a detrimental impact on a number of patients. Patients reported a deterioration of their mental health, believing they were wasting NHS resources, and some even reporting suicidal ideation.
		Patient-healthcare worker relationship	Relationship development	The components of the patient-healthcare worker relationships were reported throughout the survey responses. Healthcare workers reported attempting to build a rapport with their patients (and caregivers, if applicable). Patients and caregivers reported on the little support they received when accessing services.

Theme	**Theme description**	**Code**	**Subcode**	**Subcode description**
			Lack of information communicated	The quantity and quality of information provided by healthcare workers to patients, caregivers, or other services had an impact on the patient-healthcare worker relationship. Caregivers and patients predominantly felt that the information they were provided was not sufficient, with some not being given a full explanation of the FND diagnosis and their treatment options.
			How information is communicated	The different types of communication (such as letter, or face-to-face) were discussed. Patients wished for more direct communication. Some were not informed of their diagnosis in a

Theme	Theme description	Code	Subcode	Subcode description
				meeting, only finding out their FND diagnosis via letter.
		Shared decision-making	Collaboration	Information was provided on the collaboration between healthcare workers, patients, and caregivers, as well as the collaboration between services.
			Involvement of patients in decision-making	Patient and healthcare worker views on shared decision-marking contrasted vastly. Healthcare workers reported involving patients in treatment decisions, whereas many patients experienced the opposite. Those who were involved reported feeling fully informed of their choices and felt their opinions were taken into consideration.

Theme	**Theme description**	**Code**	**Subcode**	**Subcode description**
Impact of FND	The clinical management of FND and FND as a diagnosis had a negative impact on many patients. Respondents described how their everyday life has been adversely affected by FND, from feeling confused about their condition, to no longer being able to work or having relationships break down due to the condition.	Impact on emotions and feelings	Confusion and embarrassment	Both patients and caregivers experienced confusion or embarrassment during the clinical management of FND as they felt they were dismissed by healthcare workers.
			Frustration	Patients and caregivers experienced frustration when speaking with healthcare workers as they were made to feel they were exaggerating the FND symptoms.
			Reassured	A small amount of patients reported feelings of reassurance, as the FND diagnosis gave them an explanation of their symptom onset.

Theme	Theme description	Code	Subcode	Subcode description
			Isolation	Patients and caregivers reported feelings of isolation and abandonment. This was mainly caused by a lack of follow up from services and healthcare workers after they received their FND diagnosis.
		Impact on everyday life	Loss of trust	Accessing services led to both patients and caregivers losing trust in healthcare workers, with some refusing to attend future medical appointments.
			Health and wellbeing	Patients focused on how their FND symptoms impacted their health and wellbeing. Patients struggled with

Theme	**Theme description**	**Code**	**Subcode**	**Subcode description**
				the unpredictability of the onset and severity of their symptoms.
			Relationship breakdown	Patients and caregivers commented on how the FND diagnosis and FND symptoms led to relationship breakdowns, whether with friends or loved ones.
			Financial loss	The unpredictability and severity of FND symptoms led to financial loss, including job loss and early/forced retirement.
		Impact on mental health	Increased anxiety	Some patients found that they had an increase in anxiety and worry due to their negative experiences from

Theme	**Theme description**	**Code**	**Subcode**	**Subcode description**
				accessing health services for their FND diagnosis.
			Negative mental health	The experiences of the clinical management of FND and FND symptoms negatively impacted the mental health of both patients and caregivers.
Accessing treatments	Accessing treatments was a complex process for patients. Respondents described their experiences of FND treatments, including how patients were referred to treatment services, ongoing support	Ongoing support	Outside support	Patients provided information on how outside services (e.g., support groups, charitable organisations) have supported/are supporting them and their FND symptoms. Some patients preferred accessing support outside of the NHS, wanting camaraderie from other patients with an FND diagnosis.

Theme	Theme description	Code	Subcode	Subcode description
	and the ability of services to provide treatments.		Treatment support	Many patients focused on little or no treatments support they had received since their FND diagnosis. Those who had limited treatment support accessed complementary medicine and private care.
			Improvement in treatment support	Ideas on how treatment support could be improved in services were provided in a number of survey responses.
			Healthcare worker support	Patients who experienced a lack of healthcare worker support when attempting to access treatments often felt isolated or dismissed.

Theme	Theme description	Code	Subcode	Subcode description
		Ability to provide treatments	Treatment availability	Participants commented on how few treatments were available to manage FND symptoms, reflecting that this issue may be due to a postcode lottery effect or lengthy waiting lists.
			Improvement in treatments being offered	Perspectives on how FND treatments could be improved were offered by healthcare worker respondents. Many ideas focused on implementing an MDT approach into treatment services.

Theme	**Theme description**	**Code**	**Subcode**	**Subcode description**
Barriers to accessing resources	Resources, and barriers to accessing resources, were discussed at length by all respondent types. Participants explained how they were unable to access healthcare due to lengthy waiting lists or because of the "postcode lottery" where services were unavailable in their location.	Waiting times	Lengthy waiting times	Respondents described both their experiences of being placed on a waiting list, but also the impact of waiting lists on their symptoms.
			Removal from waiting lists	Some patients experienced being removed from waiting lists to access services without being consulted, leaving them confused or angry.
			Private healthcare	A minority of patients accessed private healthcare to bypass lengthy waiting lists for NHS care. This left some patients in considerable debt.

Theme	Theme description	Code	Subcode	Subcode description
			Results waiting time	Patients found themselves having to wait a lengthy period of time to receive test results, with some not even being informed of the outcome of the test.
			Appointment times	All respondent groups provided comments on the limited time available during appointments. Healthcare workers wished for extra time to ensure a thorough assessment was completed.
		Inability to access services	Appointment cancellations	Patients reported their experiences of healthcare appointments being cancelled, leaving them feeling worried and angry at services.

Theme	Theme description	Code	Subcode	Subcode description
			Declined access to services	Experiences of patients being declined access to services were provided by respondents. Healthcare workers discussed the reasons why patients are declined from their own service (e.g., due to a lack of funding available).
			Postcode lottery	Several patients discussed how their geographic location affected their chances of receiving timely care. Some admitted to using loved-ones addresses in order to access healthcare.
		Resource waste	Wasting patient time	Although many patients wished to be seen by services, some of

Theme	Theme description	Code	Subcode	Subcode description
				those who were able to access an appointment felt it was a waste of time and resources.
			Overuse of resources	Patients deemed conducting the same test multiple times (such as MRIs or blood tests) as a waste of NHS resources.
FND knowledge and education	Respondents shared experiences of their interactions with healthcare workers who were knowledgeable (or not) of FND. Experiences highlighted how there was a lack of knowledge or awareness of FND in healthcare services, or that	Lack of knowledge	Knowledgeable healthcare workers	Respondents provided information on FND knowledge in health services. Some were deemed to be very knowledgeable, which helped patients feel at ease.
			Lack of healthcare worker knowledge	Healthcare workers who had limited FND-specific knowledge were

Theme	Theme description	Code	Subcode	Subcode description
	there is insufficient education and training on the condition.			unaware of the condition, with some believing that FND was not a real condition.
			Lack of patient knowledge	Patients found themselves not understanding FND due to the limited information given to them when accessing services. Some were only given a website to educate themselves, leading to them becoming confused.
			Ignorance	Patients and caregivers shared how healthcare workers and the public were ignorant about FND, with many being fully unaware of the condition.

Theme	**Theme description**	**Code**	**Subcode**	**Subcode description**
		Education and training	Lack of FND specific education	Healthcare workers discussed the FND-specific training and education they received (or did not, in some cases).
Experiences of the FND diagnosis	Experiences of the diagnostic processes for FND varied widely between patient respondents. Some FND patients believed they were misdiagnosed or refused to accept their FND diagnosis, including a small number who sought further	Experiences of diagnostic testing	Rule-out diagnostic testing	Experiences of how rule-out diagnostic testing was used to diagnose FND, and perspectives on how rule-out testing should be used to diagnose FND were provided by participants.
			Ease of accessing services	Patients and caregivers provided detailed responses in describing their experiences being able to access FND-specific diagnostic services

Theme	Theme description	Code	Subcode	Subcode description
	private tests to confirm their condition.		Effect of FND diagnosis on other conditions	Patients shared their perspectives on how their FND diagnosis impacts on the diagnosis and treatment of their other health conditions.
		Misdiagnosis	FND misdiagnosis	Some patient respondents believed they were misdiagnosed with FND, leading them to paying for private tests for a different diagnosis.
			Misdiagnosis of another condition	A small number of patients found that they were misdiagnosed with another condition instead of FND, leading to worsened symptoms and becoming unwell.

Theme	Theme description	Code	Subcode	Subcode description
			Acceptance of FND	Patients discussed their experiences of accepting (or not accepting) their diagnosis. Some admitted to struggling to accept their diagnosis due to a lack of information given during medical appointments.

Appendix 8: Ethical approval letters

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Prof Stephen Holland
Chair, Health Sciences Research Governance Committee

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18 December 2020

Miss D Varley
University of York
Department of Health Sciences
York
YO10 5DD

Dear Danielle

***HSRGC/2020/391/B:* CD/FND surveying research study**

Thank you for your email of 2 December 2020, including a detailed response to HSRGC feedback and updated study documents. I am pleased to confirm by Chair's Action that the amended project is now approved.

If you have any queries regarding the decision or feedback, or make any further substantial amendments to the study, please contact me.

Yours sincerely

S. Holland

Stephen Holland
Chair: HSRGC

cc. Prof Christina van der Feltz-Cornelis, Dr Dimitris Lagos

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13 May 2022

Ms Danielle Varley
University of York
Department of Health Sciences
Heslington
York
YO10 5DD

Dear Danielle

***HSRGC/2022/508/H:* FND experiences interview study**

Thank you for submitting your project to the Health Sciences Research Governance Committee for approval. The committee considered the application at its meeting on 9 May 2022.

The committee approved the project. I was asked to provide the following feedback.

- There are occasional references on the submission form to 'FND/CD'. The committee assumed 'CD' refers to 'conversion disorder' and is being treated as equivalent to FND. If this not the case, please contact me to confirm what 'CD' refers to.
- Section 12 of the submission form states, 'If enough participants cannot be sought via the survey study, convenience sampling will also be used to recruit to this study. This will involve recruiting via advertising on social media, online support forums, word of mouth by healthcare workers and services, and FND charities and organisations (such as FND Hope UK).' If you do recruit by convenience sampling, please get back to me with more details as to how you will approach prospective participants, including the text of outward-facing documents (e.g., social media adverts), which I will review as a Chair's Action.
- Section 11 of the submission form: the committee suggest that transcribing an audio recording from each interview 'within 24 hours' sounds unrealistic, and advise giving yourself more time to complete the transcribing.
- Section 16 and 17: the committee pointed out that the study might elicit information requiring disclosure (e.g., professional misconduct or neglect) and that some participants might display worrying signs of serious distress. In either event, in the first instance you should discuss the matter with you supervisors who will be able to advise as to how best to proceed.

- Section 26 of the submission form states, 'data provided by participants will be gathered and kept in accordance with the Data Protection Act (1998)'. Your study falls under 'UK GDPR and Data Protection Act (2018)', so this should be clearly stated on the information sheet (IS). In addition, the IS only includes one link to a GDPR-related university webpage. In order to be GDPR compliant you need to include all the following links on the IS, which are on the HSRGC IS template:

  https://www.york.ac.uk/records-management/dp/
  https://www.york.ac.uk/records-management/dp/guidance/gdprcompliantresearch/
  https://www.york.ac.uk/records-management/dp/your-info/generalprivacynotice/
  https://www.york.ac.uk/healthsciences/research/trials/trials-gdpr/
  https://www.york.ac.uk/healthsciences/research/trials/trials-gdpr/research-partcipants/

The committee are happy for you to take up this feedback in supervision and do not require further review, but please send redrafted outward-facing study documents for our records. In the meantime, if you have any queries regarding the decision or feedback, or make any substantial amendments to the study, please contact me.

Finally, if you intend to submit this letter or any other correspondence from the HSRGC as part of your assessed work (e.g., to demonstrate that your study has ethical approval) please make sure you edit the letter to maintain anonymity.

Yours sincerely

S. Holland

Stephen Holland
Chair: HSRGC

cc: Prof Christina van det Feltz-Cornelis, Dimitris Lagos

Appendix 9: Interview Topic Guides

Caregiver Topic Guide

Introduction

- The aim of this interview to talk about your experiences and perspectives of the diagnostic and treatment processes for functional neurological disorder (FND).
- I am interested in hearing your views on this topic
- Your responses will be kept confidential and any identifiable information will be removed when the results are published

If the participant did not take part in the previous survey study, they will be asked questions highlighted in yellow

Part A: Participant information

- How do you identify? (female/male/NB)
- What is your age?
- What is your ethnicity?
- Where are you geographically based (county level)?
- Please could you tell me if the person you support has received a diagnosis of FND?
    - If so, when did they receive the diagnosis?
    - If not, are they currently undergoing diagnostic tests/been unable to access services?
- For how long have you provided support to the person with FND?
- On average, how many hours per week do you spend in your caregiver role?
- What type(s) of caregiving support do you provide? (Such as transport, emotional support, assisting with tasks)
- What, if anything, do you think is linked to the onset of FND? (Such as an operation, adverse childhood event, illness)?
    - Why do you think this?

Part B: Diagnostic information

- Which healthcare workers were involved when the person you support were undergoing diagnostic tests? (Such as a neurologist, A&E doctor, nurse)
- Which services did you attend during the diagnostic process?
- What tests were used to help diagnose the person you support? (e.g. blood sample, EEG, neurological exam)
- Which healthcare worker(s) gave the person you support their FND diagnosis? (e.g. neurologist, psychiatrist)
- Please could you describe your experience of the diagnostic process for FND?
    - Attitudes of healthcare workers
    - Attitudes of family/friends
    - Ease of access to services
    - Barriers/facilitators to the diagnostic process
    - Waiting times
- Please could you describe the support the person you support received during the diagnostic process?
- Please could you describe the support you received during the diagnostic process?

    - What support would you have liked to have received?
    - Do you feel that the healthcare workers involved were supportive of you and the person you support?
- Please could you tell me about how the person you support received their FND diagnosis?
    - What happened after the diagnosis?

Part C: Treatment process

- Has the person you support received any treatments/therapies/interventions for FND? (Such as CBT, medication, hypnosis)
    - If so, how long have the received these treatments?
    - Do you think the treatments are effective?
- Please could you describe your experience of the treatment process for FND?
    - Attitudes of healthcare workers
    - Attitudes of family/friends
    - Ease of access to treatments
    - Barriers/facilitators to treatments
    - Waiting times
    - Involvement in deciding which treatments to receive
- Please could you tell me about any support the person you support had while receiving treatment?
    - What support would you have liked them to have received?
    - Do you feel that the healthcare workers involved were supportive of you and the person you care for?

Part D: Final questions

- How do you think caregivers should be involved in the diagnostic and treatment processes for FND?
- Are there any other experiences or perspectives on the diagnostic and treatment processes you would like to share?

Healthcare worker Topic Guide

Introduction

- The aim of this interview to talk about your experiences and perspectives of the diagnostic and treatment processes for functional neurological disorder (FND).
- I am interested in hearing your views on this topic
- Your responses will be kept confidential and any identifiable information will be removed when the results are published

If the participant did not take part in the previous survey study, they will be asked questions highlighted in yellow

Part A: Participant information

- How do you identify? (female/male/NB)
- What is your age?
- What is your ethnicity?
- Where are you geographically based (county level)?
- What is your job title and your service type?
- How long have you worked with FND patients?
    - How many FND patients do you typically see per year?
    - How would you rate your knowledge/expertise of FND?
    - Please describe the training you have received on FND
- What, if anything, do you think is linked to the onset of FND? (Such as an operation, adverse childhood event, illness)?
    - Why do you think this?

Part B: Diagnostic information

- Which assessments have you used, or helped with, in the past two years to diagnose a patients with FND?
    - What training/supervision have you received to deliver the diagnostic assessment(s)?
- Which assessments do you think are necessary to diagnose (or assist in diagnosing) a patient with FND?
    - Why is this?
- Do you think that the diagnostic processes your service uses are suitable for FND patients?
    - Why is this?
- Which diagnostic tools do you think should be used in order to diagnose FND?
- Please could you describe your experience of the diagnostic process for FND?
    - Attitudes of other healthcare workers
    - Attitudes of patients/caregivers
    - Barriers/facilitators
    - Waiting times
- How does a patient receive an FND diagnosis in your service?
    - Who is involved?
    - What happens after the diagnosis is given

Part C: Treatment process

- If applicable, what treatment options does your service provide for patients diagnosed with FND?

- What treatment options do you think should be used in the treatment of FND?
- Please could you describe your experience of the treatment process for FND?
    - Attitudes of other healthcare workers
    - Attitudes of patients/caregivers
    - Ease of access to treatments
    - Barriers/facilitators to treatments
    - Waiting times
    - Patient involvement in deciding which treatments to receive
- Please could you tell me about any support patients receive from your service/services while receiving treatment?
    - What support would you like them to receive?
- Do you feel that new approaches or treatments need to be implemented into your service to support patients with an FND diagnosis?
    - Why is this?

Part D: Final questions

- Are there any other experiences or perspectives on the diagnostic and treatment processes you would like to share?

Patient Topic Guide

Introduction

- The aim of this interview to talk about your experiences and perspectives of the diagnostic and treatment processes for functional neurological disorder (FND).
- I am interested in hearing your views on this topic
- Your responses will be kept confidential and any identifiable information will be removed when the results are published

If the participant did not take part in the previous survey study, they will be asked questions highlighted in yellow

Part A: Participant information

- How do you identify? (female/male/NB)
- What is your age?
- What is your ethnicity?
- Where are you geographically based (county level)?
- Please could you tell me if you have received a diagnosis of FND?
    - If so, when did you receive the diagnosis?
    - If not, are you currently undergoing diagnostic tests/been unable to access services?
- What, if anything, do you think is linked to the onset of FND? (Such as an operation, adverse childhood event, illness)?
    - Why do you think this?

Part B: Diagnostic information

- Which healthcare workers were involved when you were undergoing diagnostic tests? (Such as a neurologist, A&E doctor, nurse)
- Which services did you attend during the diagnostic process?
- What tests were used to help diagnose you? (e.g. blood sample, EEG, neurological exam)
- Which healthcare worker(s) gave you your FND diagnosis? (e.g. neurologist, psychiatrist)
- Please could you describe your experience of the diagnostic process for FND?
    - Attitudes of healthcare workers
    - Attitudes of family/friends
    - Ease of access to services
    - Barriers/facilitators to the diagnostic process
    - Waiting times
- Please could you describe the support you received during the diagnostic process?
    - What support would you have liked to have received?
    - Do you feel that the healthcare workers involved were supportive of you and your condition?
- Please could you tell me about how you received your FND diagnosis?
    - What happened after the diagnosis?

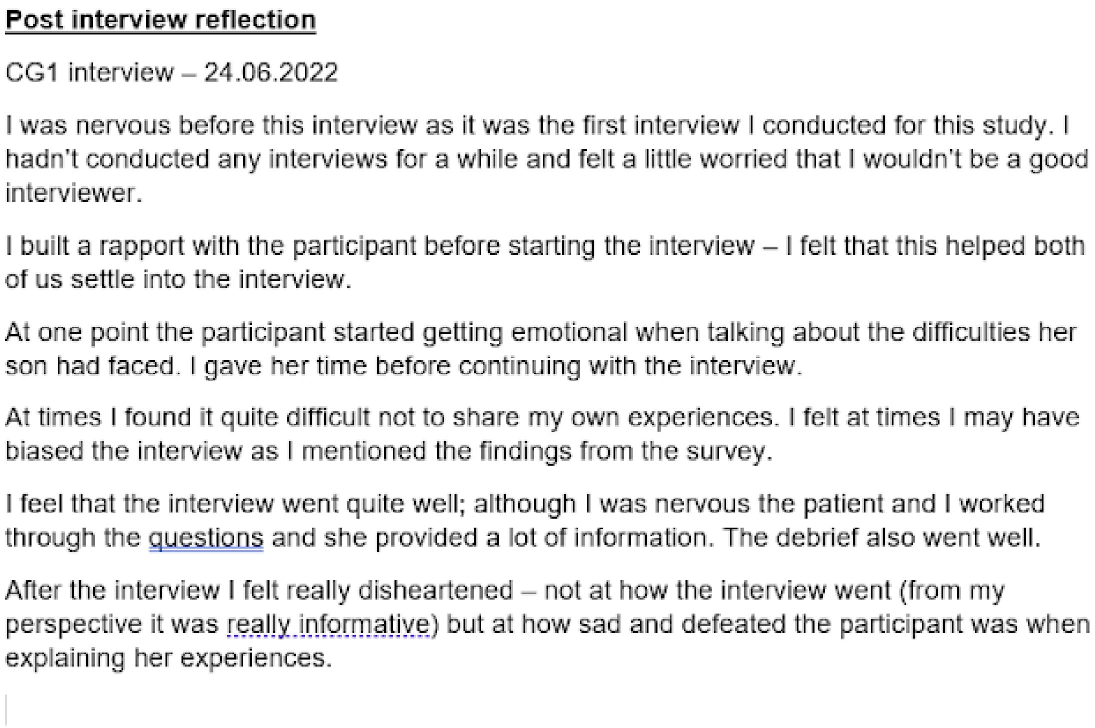
Part C: Treatment process

- Have you undertaken any treatments/therapies/interventions for FND? (Such as CBT, medication, hypnosis)
  - If so, how long have you received these treatments?
  - Do you think they are effective?
- Please could you describe your experience of the treatment process for FND?
  - Attitudes of healthcare workers
  - Attitudes of family/friends
  - Ease of access to treatments
  - Barriers/facilitators to treatments
  - Waiting times
  - Involvement in deciding which treatments to receive
- Please could you tell me about any support you have had while receiving treatment?
  - What support would you have liked to have received?
  - Do you feel that the healthcare workers involved were supportive of you and your condition?

Part D: Final questions

- Are there any other experiences or perspectives on the diagnostic and treatment processes you would like to share?

Appendix 10: Excerpts from reflexive diary



Post interview reflection

CG1 interview – 24.06.2022

I was nervous before this interview as it was the first interview I conducted for this study. I hadn't conducted any interviews for a while and felt a little worried that I wouldn't be a good interviewer.

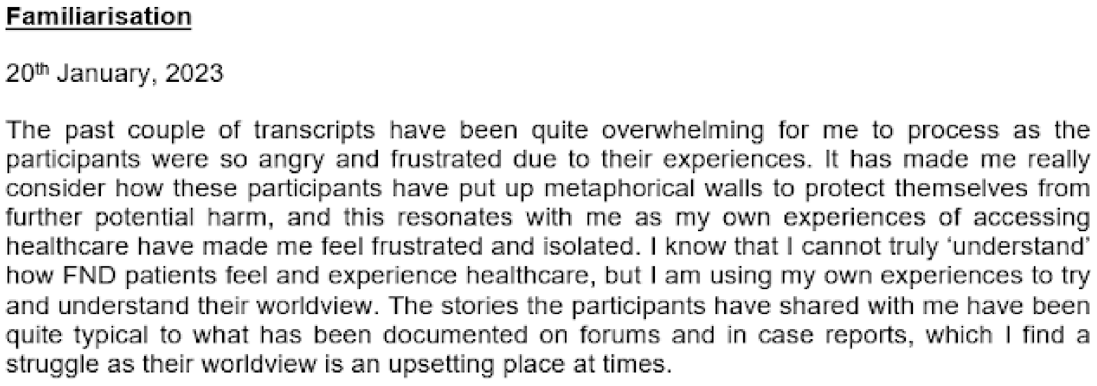
I built a rapport with the participant before starting the interview – I felt that this helped both of us settle into the interview.

At one point the participant started getting emotional when talking about the difficulties her son had faced. I gave her time before continuing with the interview.

At times I found it quite difficult not to share my own experiences. I felt at times I may have biased the interview as I mentioned the findings from the survey.

I feel that the interview went quite well; although I was nervous the patient and I worked through the questions and she provided a lot of information. The debrief also went well.

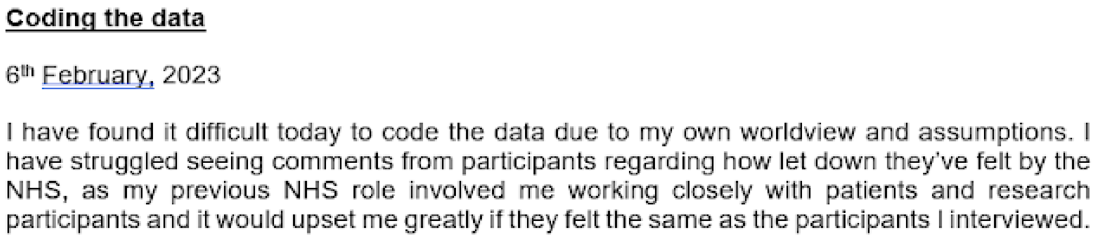
After the interview I felt really disheartened – not at how the interview went (from my perspective it was really informative) but at how sad and defeated the participant was when explaining her experiences.



Familiarisation

20th January, 2023

The past couple of transcripts have been quite overwhelming for me to process as the participants were so angry and frustrated due to their experiences. It has made me really consider how these participants have put up metaphorical walls to protect themselves from further potential harm, and this resonates with me as my own experiences of accessing healthcare have made me feel frustrated and isolated. I know that I cannot truly 'understand' how FND patients feel and experience healthcare, but I am using my own experiences to try and understand their worldview. The stories the participants have shared with me have been quite typical to what has been documented on forums and in case reports, which I find a struggle as their worldview is an upsetting place at times.



Coding the data

6th February, 2023

I have found it difficult today to code the data due to my own worldview and assumptions. I have struggled seeing comments from participants regarding how let down they've felt by the NHS, as my previous NHS role involved me working closely with patients and research participants and it would upset me greatly if they felt the same as the participants I interviewed.

Appendix 11: COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	135
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	N/A
Occupation	3	What was their occupation at the time of the study?	147
Gender	4	Was the researcher male or female?	147
Experience and training	5	What experience or training did the researcher have?	147
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	135-136
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	136
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	147
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	137-138
Participant selection			
Sampling	10	How were participants selected? e.g. purposive,	135

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	135
Sample size	12	How many participants were in the study?	135
Non-participation	13	How many people refused to participate or dropped out? Reasons?	135
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	135
Presence of nonparticipants	15	Was anyone else present besides the participants and researchers?	149
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	254-259
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	136
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	N/A
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	136
Field notes	20	Were field notes made during and/or after the interview or focus group?	136
Duration	21	What was the duration of the interviews or focus group?	252
Data saturation	22	Was data saturation discussed?	N/A
Transcripts returned	23	Were transcripts returned to participants for comment and/or correction?	139
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	139
Description of the coding tree	25	Did authors provide a description of the coding tree?	145

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Derivation of themes	26	Were themes identified in advance or derived from the data?	141
Software	27	What software, if applicable, was used to manage the data?	141
Participant checking	28	Did participants provide feedback on the findings?	N/A
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Quotations have been embedded throughout chapter 5 (pages 266-326)
Data and findings consistent	30	Was there consistency between the data presented and the findings?	The author has ensured the findings and data presented remained consistent throughout the chapter (266-326).
Clarity of major themes	31	Were major themes clearly presented in the findings?	The major themes derived from the interviews are presented in chapter 5 (266-326).
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	Diverse cases have been presented and discussed throughout chapter 5. Minor themes have been presented alongside the major themes (266-326).

Appendix 12: Description of interview themes

Descriptions of the themes/sub-themes derived from the reflexive thematic analysis

Theme/ sub-theme	Description
The impact of FND The overall impact of FND on the patient, their caregiver, and loved ones was a major focus throughout the interviews and subsequent analysis. Participants focused on how FND not only had a negative impact on a patient's physical health, but also affected their mental wellbeing due to their loss of livelihood and unpredictability of symptoms.	
FNDs impact on the self	The unpredictability of when symptoms would occur, and the unpredictability of the severity of symptoms was severely detrimental to patient mental health. This unpredictability of symptom occurrence and severity led to many patients losing their independence as they were unable to complete everyday tasks (such as cleaning or driving) as they were worried that they may have a seizure or drop attack and hurt themselves. Being unable to drive led to many patients feeling isolated and alone in their homes. Loss of independence was also impacted by the loss of livelihood as many patients were forced to leave their job or were medically retired. While being able to access benefits to support their loss of income, many patients felt embarrassed or unable to apply for a disability living allowance or personal independence payment award.
FNDs impact on the family unit	FND had numerous negative effects not only on the patient, but also their family. Patients and their family members were concerned how FND impacted them financially, physically, and emotionally. Family and relationship dynamics were irrevocably altered by the condition, with housing arrangements needing to be adapted to ensure the person with the FND diagnosis would not come to harm, and children's resilience being tested and relationships and marriages breaking down due to the strain of FND and its symptoms.
Impact on friendships	Friendships were both positively and negatively impacted by FND. While some patients and caregivers found that the condition strengthened a handful of friendships, most friendships ended due to people feeling uncomfortable or patients and caregivers being unable to attend events. Those who had received their diagnosis a

Theme/ sub-theme	**Description**
	long time before the interview were much more candid when discussing changes to friendships than those with a recent diagnosis, perhaps highlighting that time was needed to accept these changes. Lastly, patients and caregivers reported avoiding certain topics or not reporting the FND diagnosis to friends to preserve the friendship.
FNDs Impact on healthcare workers	Healthcare workers felt enormous pressure when working with FND patients as they were worried they may misdiagnose or be unable to support them. Healthcare workers were concerned about failing FND patients as there were not many other healthcare workers available or aware of the condition to suitably support them, yet were accepting that sometimes they could not provide further support to some patients.
Support: ‘it takes a village’ Participants from all three population groups deemed support from a range of proximal and distal sources are vital to improve quality of life and outcomes for the FND patient. Participants provided experiences on the support (or lack of support) received by healthcare workers, the extent of which caregivers should be involved in healthcare decisions, and support from other patients (peer support).	
Support received from healthcare workers	While the healthcare workers interviewed in this study were supportive of FND patients and aimed to provide quality care, patient and caregivers experiences of support from healthcare workers were predominantly negative. Patients and caregivers experienced negative attitudes and dismissive behaviours from healthcare workers, with some being told they were malingering. Participants disclosed how few healthcare workers were interested or willing to work with FND patients, particularly those who had limited awareness or expertise in the condition.
Support from the community	Peer support from online and community groups were the accessed by the majority of patient and caregiver participants. This was to the chagrin of some healthcare workers, who admitted they were important yet worried about the ‘quality control’ of these groups. Peer groups helped patients develop a sense of belonging and able to ask questions about their symptoms or treatment options to others who

Theme/ sub-theme	**Description**
	had a true understanding of their disorder. Support and advocacy from friends were also discussed by participants, as well as caregivers of children providing support to other caregivers.
Support from caregivers	Caregivers were seen as an important part of the clinical management of FND, providing invaluable information to healthcare workers on the symptoms experienced by patients and also symptom severity. However, the extent of how involved caregivers were involved was discussed, with some healthcare workers stating that caregivers can sometimes negatively affect care. Caregivers reflected on the support they would like to receive to reduce caregiving stress and burden, with many wishing they had the chance to talk through their thoughts and feelings to an individual outside of their situation.
Support from family and loved ones	Family members and loved ones were willing to provide support, despite their lack of understanding of FND and its associated symptoms. Family members provided a wide range of support, from childcare to offering medical advice. The differences of acceptance of the condition and ability to provide support differed from parents who had young children versus those with grown children, with young children being much more resilient and able to support their parent when suffering from their FND symptoms.
Support from school and work	The support offered by school and workplaces differed immensely. Schools were unwilling to support children with an FND diagnosis, with participants discussing how they were dismissive to their child's needs. Workplaces offered a variety of support to FND patients and caregivers, including making suitable adjustments to the workplace, time away from the office, or home or hybrid working.
Life after diagnosis Reflections on the changes to everyday life were discussed by many of the study's participants. Participants reflected on learning how to adapt to the 'new normal' and how they came to accept their diagnosis and the FND 'label'. Discussions on treatments (and whether patients were even offered treatments) and outcomes were held.	
Adapting to the new normal	Patients initially struggled to come to terms with their recent FND diagnosis, finding it difficult to accept due to the adaptations put in

Theme/ sub-theme	**Description**
	place in their home and having to use mobility aids to ensure their safety. Patients grieved for their past self, yearning to be able to the same physical activities or hobbies they did before the onset of FND symptoms. While some found it difficult to accept their new normal, others became more empathetic and understanding of those around them.
Treatments: the road to nowhere	Attempting to access treatments and treatment services was a frustrating experience for many participants. Many were unable to access the support they needed due to waiting times or not being referred to appropriate health services. Caregivers and patients researched self-management techniques and coping strategies to lessen FND symptoms, with some developing their own physiotherapy programme and others learning to meditate. Readiness for treatment was discussed, with some patients feeling apprehensive or ambivalent about attending treatment appointments. Healthcare workers attempted to support those feeling apprehensive, and worked with those patients to determine whether they should access care now or in the future.
Accepting and believing the 'FND label'	Participants reflected on FND and the acceptance and beliefs surrounding the FND diagnosis. Some patients felt they had to accept the diagnosis as there were no other explanations for their symptoms, yet other sought private assessments to explore whether they were misdiagnosed as they did not want to accept their FND diagnosis. The beliefs of healthcare workers were highlighted, with some in wider services refusing to believe FND is a 'real' condition, much to the frustration of the patients to whom they were speaking.
The art of communication Participants reflected on the importance of communication between healthcare workers, services, and patients during the clinical management of FND. The language and analogies used by healthcare workers both helped and hindered diagnostic explanations, leading to some bewildered patients and caregivers needing to conduct their own research to understand their symptoms and their newly diagnosed disorder. Lastly, participants focused on the patient-healthcare worker relationships, reflecting on how communication is imperative for its development.	

Theme/ sub-theme	**Description**
The patient-healthcare worker relationship	The lack of communication between healthcare workers and patients hindered the development of the patient-healthcare worker relationship. Patients perceived that healthcare workers were not empathetic or understanding of their needs or feelings and were regularly ignored when accessing services. Patients frequently reported no shared decision-making taking place, finding that healthcare workers simply stated what treatments would be implemented. In contrast, healthcare worker participants perceived they listened to the needs of patients and their concerns.
Information sharing	Healthcare worker and patient perspectives differed greatly on the communication between the two population groups and how information relating to the condition was relayed. Patients perceived that information from healthcare workers and services was not shared, or not shared clearly with them, leading to confusion, bewilderment and worry. This confusion led to patients and caregivers conducting research to find information, much to the dismay of the healthcare worker participants. Healthcare workers adapted their communication styles to ensure the information they shared was understood by patients. Signposting to resources and organisations was a contentious issue for some healthcare workers who worried about the ‘quality control’ of the information or resources given to patients.
Communication between healthcare workers and services	Experiences of the communication between healthcare workers and services varied, with patients sharing communication was limited, whereas healthcare workers shared their experiences of how effective communication between healthcare workers employed in different services led to patients being given medical appointments in a suitable time frame and collaboration between services.
Resources: the barrier to effective and timely care Resource use and barriers to accessing services were key conversation points for all participants. Participants reflected on the waiting times for diagnostic and treatment services appointments and the utilisation of privatised healthcare. Lastly, the implementation of multidisciplinary teams as a facilitator to timely care were discussed by healthcare workers.	

Theme/ sub-theme	**Description**
Waiting times	Waiting times differed immensely across services, with some only having waiting lists of a few weeks, whereas others had waiting lists over two years long. Long waiting lists led to some patients ‘falling through the cracks’ and never receiving a treatment appointment. A minority of patients and caregivers utilised private healthcare to avoid these lengthy waiting times, to mixed results.
Barriers to accessing resources	Healthcare workers reflected on their experiences of the postcode lottery and how it affected their own services. The postcode lottery caused patients issues in accessing appropriate care in a timely fashion or even unable to access appropriate services as there were no services in their geographic location. Patients and caregivers experienced problems with being unable to arrange appointments due to healthcare worker availability and training, as well as experiencing no continuity of care when accessing services. Healthcare workers reported how multidisciplinary teams can be a facilitator to improving access to care.

Appendix 13: PPI Information

PPI member information: As discussed in Sections 3.3.1 and 3.5, PPI representatives were involved in all three stages of this thesis. Five PPI members provided information and perspectives on the clinical management of FND, three were patients with a diagnosis of FND and the remaining two were caregivers.

Demographic information: Patient PPI members: two members were female and one male. All three were students at the time of the thesis (one studying for an undergraduate degree and two studying for a postgraduate degree). At the time of participation, two were based in North Yorkshire and one was based in London. All three identified as White-British and were aged between 23-31 years.

Caregiver PPI members: one member was female and one male. Both were retired (no details were provided on their previous careers) and were providing full time care to their adult children with a diagnosis of FND. At the time of participation, one was based in North Yorkshire and the other was based in the North-East of England. Both identified as White-British and were aged between 60-65 years.

Recruitment information: PPI members were recruited via two different means; two members were known by the author as they were participants of a research study the author was previously involved. The author invited them to support the research conducted as part of this thesis by providing their perspectives and thoughts on each element of the study.

The remaining three (one patient and two caregivers) unknown to the author before the research commenced. They became involved as PPI members as each had independently contacted the author during the consultation exercise (conducted as part of the scoping review) to share potentially relevant evidence. After conversing over email and all three independently provided their own perspectives of the clinical management of FND in the United Kingdom, the author asked to meet (over Zoom) with each PPI member to discuss their perspectives and experiences as she thought this would be more personable. After each respective meeting, the author asked the individuals if they would like to be involved as a PPI member. All five PPI members were happy to share their perspectives, comment on research ideas and participant-facing documents and provide information pertinent to the work.

Appendix 14: Patient information sheets

An online survey exploring the experiences of the diagnosis and treatment processes for Functional Neurological Disorder (FND)

You are invited to participate in a research study titled ‘An online survey exploring the experiences of the diagnosis and treatment processes for Functional Neurological Disorder (FND)’. Before you decide to take part in the research, please read the following information.

What is the purpose of this study?
Functional Neurological Disorder (FND) is a condition in which a person experiences neurological symptoms (such as tremors or impaired movement) that are not caused by a neurological condition. Diagnosing FND is challenging both for the patient and healthcare worker as there are limited diagnostic tools. This can be particularly frustrating for the patient as they are undergoing tests which may not lead to a diagnosis. The experiences of those involved (such as patients, their caregivers, and healthcare workers) in the diagnosis and treatment of FND have not been widely discussed or officially documented.

This study aims to explore the experiences patients, caregivers, and healthcare workers who have been involved in the diagnosis and treatment of FND. The findings from this study will be used to develop the questions to be asked in future interviews exploring FND. This study has been granted ethical approval from the University of York HRSGC ethics committee (ID number: HSRGC/2020/391/B).

Why have I been asked to participate?
We are looking for:

- Adults (aged 18+) who have received a diagnosis of FND, undergoing diagnosis of FND, suspect they have FND, or have been unable to access services to obtain a FND diagnosis.
- Adults (aged 18+) who provide support for a person who has received a diagnosis of FND.
- Healthcare workers who have been involved in the diagnosis and treatment of those with FND.

to complete this study.

The study will involve completing a survey which will take approximately 15-20 minutes to complete, depending on the length of your answers. Study participation is voluntary.

Some people may find it difficult to complete the survey online due to staring at a computer screen or may not have suitable computer or internet access. If you would prefer to complete the survey by phone/teleconference (e.g. Zoom) or by post, please contact Danielle Varley (email address: Danielle.varley@york.ac.uk).

All information collected during the study will be kept confidential and will be stored in a secure, password protected, encrypted computer database at the University of York. Any identifiable data (such as your contact details if you wish to take part in the interviews being held in the future) will be stored on a separate secure database and only the researcher and study supervisors will have access to the survey data. If you wish to take part in the future interviews, the data you provide in the survey will be linked to the interview using a unique participant code.

By clicking the arrow button, you acknowledge that you agree to take part in the study, and your participation is voluntary.

An interview study investigating the experiences of the diagnosis and treatment processes for Functional Neurological Disorder (FND)

Participant Information Sheet

You are invited to participate in a research study titled *'An interview study investigating the experiences of the diagnosis and treatment processes for Functional Neurological Disorder (FND)'*

Before you decide to take part in the research, please read the following information.

What is the purpose of this study?

Functional Neurological Disorder (FND) is a condition in which a person experiences neurological symptoms (such as tremors or impaired movement) that are not caused by a neurological condition.

The experiences of those involved (such as patients, caregivers, and healthcare workers) in the diagnosis and treatment of FND have not been widely discussed or officially documented. This study aims to explore the experiences (both positive and negative) of those involved in the diagnosis, treatment, and care of FND.

Who is doing the study?

This study is being conducted by Danielle Varley (PhD student) from the Department of Health Sciences at the University of York. The study is part of a PhD project and is being funded by the University of York. The study supervisors are Prof. Christina van der Feltz-Cornelis (Christina.vanderfeltz-cornelis@york.ac.uk) and Dr Dimitris Lagos (dimitris.lagos@york.ac.uk).

Why have I been asked to participate?

This study aims to explore the experiences patients, caregivers, and healthcare workers who have been involved in the diagnosis and treatment of FND. We are looking for:

- Adults (aged 18+) who have received a diagnosis of FND, undergoing diagnosis of FND, suspect they have FND, or have been unable to access services to obtain a FND diagnosis.

- Adults (aged 18+) who provide support for a person who has received a diagnosis of FND.

- Healthcare workers who have been involved in the diagnosis and treatment of those with FND.

Do I have to take part? What if I change my mind?

Taking part in the study is completely voluntary; you do not have to take part if you do not wish to do so. If you decide to take part in the study, you will be asked to complete an online or paper consent form.

If you consent to take part in the study and then change your mind at any point, you are able to do so and do not have to give a reason why. If you decide to withdraw from the study before the analysis has been conducted (September 2022), any data or information already obtained from you will be destroyed.

What will be involved if I take part in this study?

If you decide to take part in the study, you will be asked to share your experiences by taking part in an interview. The interview will take approximately 45-60 minutes to complete, depending on the length of your answers. The interview can take place over the phone, via videoconference call (e.g. Zoom or Skype), or in person. The interview will be audio- or video-recorded.

Once your interview has been transcribed (typed up) by the researcher, you may be asked to read through the transcript to check that your answers have been interpreted accurately.

What are the benefits of taking part?

You may benefit from taking part in this research as you will be able to share your experiences. The information you provide may potentially inform future practice. In addition, you may gain personal satisfaction from completing the interview.

As a thank you for completing the interview, you are given the option to be entered into a prize draw (£25 Love2shop voucher per participant group). The prize draw will be drawn at the end of the study (Autumn 2022).

What are the risks of taking part?

Some of the questions asked in the interview may cover topics you find upsetting or distressing. If this happens, you will be able to take a break from the interview or withdraw from the study.

If you are taking part in an online interview: There are minimal risks associated with looking at a computer screen for long periods of time (such as eye strain). Please take breaks from the interview if this becomes a problem.

How will the information and personal data I give be handled?

If you decide to take part in the study, you will be given a unique participant code to make sure your data remains confidential. All information collected during the study will be kept confidential and will be stored in a secure, password protected, encrypted computer database at the University of York. Any identifiable data will be stored on a separate secure database and only the researcher and study supervisors will have access to this data. If you participated in the previous online survey study, the data you provided in the survey will be linked to your interview data using your unique participant code. Data will be handled, processed, stored and destroyed as per University of York policy and the Data Protection Act (2018).

All information and data gathered during this research will be stored in line with the UK General Data Protection Regulation and Data Protection Act (2018). Information on the GDPR Act can be accessed via the following webpages:

- https://www.york.ac.uk/records-management/dp/
- https://www.york.ac.uk/records-management/dp/guidance/gdprcompliantresearch/
- https://www.york.ac.uk/records-management/dp/your-info/generalprivacynotice/
- https://www.york.ac.uk/healthsciences/research/trials/trials-gdpr/

- https://www.york.ac.uk/healthsciences/research/trials/trials-gdpr/research-partcipants/

Information will be kept for 3 years after the study has finished. Your information may be looked by the study supervisors to check that the study is being carried out correctly.

What will happen to the results of the study?

The results of the study will be published in scientific journals and a summary of the findings will be made available on online forums and social media pages. Findings will include pseudonymous quotes from the completed interviews. No identifiable information will be included in the results.

Who has reviewed and approved this study?

This study has been reviewed and approved by the University of York’s Department of Health Sciences Research Governance committee on 9th May, 2022.

Who do I contact in the event of a complaint?

If you have a concern about this study, you can speak to the research team who will do their best to answer your question. Contact details are listed at the end of this information sheet. If you have a complaint about this study, please contact the study’s supervisors: Prof. Christina van der Feltz-Cornelis (Christina.vanderfeltz-cornelis@york.ac.uk) and Dr Dimitris Lagos (dimitris.lagos@york.ac.uk). If you have a complaint on how your personal data has been handled, please contact the University’s Data Protection Officer (dataprotection@york.ac.uk) or the Information Commissioner’s Office (www.ico.org.uk/concerns).

Support organisations

If you would like support for your diagnosis or for providing support for a family member/friend, please contact your GP or the service(s) providing treatment. Additionally, you can access support from groups such as:

FND Hope UK	Email: hope@fndhope.org	Website: https://fndhope.org/
Mind	Tel:0300 123 3393	Website: www.mind.org.uk
Carers UK	Tel: 0808 808 7777	Website: https://www.carersuk.org/

Who do I contact for more information about the study?

If you would like to have more information about the study or ask any questions about taking part, please contact Danielle Varley at Danielle.varley@york.ac.uk

Thank you for taking the time to read this information sheet

Appendix 15: Study consent forms

An online survey exploring the experiences of the diagnosis and treatment processes for Functional Neurological Disorder (FND)

By clicking the arrow button, you acknowledge that you agree to take part in the study, and your participation is voluntary.

The following questions are optional:

2. As a thank you for completing the survey, you are given the option to be entered into a prize draw (a £25 Love2shop voucher). The prize draw will be drawn at the end of the study (Spring 2022).

Would you like to be entered into the prize draw?

☐ Yes
☐ No

If I win the prize draw, please contact me using the following email address/phone number:

[Enter phone number here]

3. The findings from this study will be used to develop the questions to be asked in future interviews exploring FND/CD.

I agree to be contacted to take part in an interview in the future to talk about my experiences with functional neurological disorder. I agree to provide my contact details and understand that a researcher will contact me in the future (in 2022) to arrange the interview date. I understand that if I no longer want to take part in the interview, I can withdraw at any time without needing to give any reason.

☐ Yes
☐ No

4. I agree to be contacted to take part in the future interviews. Please contact me using the following email address/phone number (please also add your name to the below box):

☐ Yes
☐ No

[Enter contact details here]

An interview study investigating the experiences of the diagnosis and treatment processes for Functional Neurological Disorder (FND)

Consent Form

	Please confirm agreement to each statement by ticking 'yes' in each row
I confirm that I have read and understand the participant information sheet [V1 09062022] and have had the opportunity to ask any questions.	Yes / No
I understand that my participation is voluntary and that I am free to withdraw at any time without needing to give any reason.	Yes / No
I have received satisfactory answers to all my questions	Yes / No
I have received enough information about the study	Yes / No
I understand that any information I provide, including personal data, will be kept confidential, stored securely and only accessed by those carrying out the study.	Yes / No
I understand that my interview will be audio-recorded/videoed.	Yes / No
I understand that any information I give may be included in published documents. I understand that any information I give will be pseudonymised.	Yes / No
I agree to take part in this study.	Yes / No

Optional: I wish to be entered into the £25 Love2Shop prize draw. If I win, I consent to be contacted to by the researcher. Please contact me using the details below Tel no.: ____ Email address: _____________________________________	Yes / No
Participant Signature …………………………………………………………… Date ___/____/___	
Name of Participant	
Researcher Signature ………………………………………………………….. Date ___/____/___	
Name of Researcher	

Appendix 16: Freedom of information requests

NHS Trust/ Health board	**Please report the number of NHS Functional neurological disorder/conversion disorder/functional seizure specific departments or centres in your Trust**	**Please report the most common diagnostic tests used in your Trust to diagnose patients with functional neurological disorder/conversion disorder/functional seizures in the last 5 years**	**Please report the most common treatments used in your Trust to support patients with Functional neurological disorder/conversion disorder/functional seizures in the last 5 years**	**Please report the number of patients in your Trust diagnosed with Functional neurological disorder/conversion disorder/functional seizures in the last 5 years**
NHS Shetland	0	In accordance with FOISA s 17(1), NHS Shetland confirms that it does not hold the information requested as the responsibility for the diagnosis of NHS Shetland patients with this condition lies with NHS Grampian.	In accordance with FOISA s 17(1), NHS Shetland confirms that it does not hold the information requested as the responsibility for the diagnosis of NHS Shetland patients with this condition lies with NHS Grampian.	From 01/01/2018 to 23/12/2022 the number of patients newly diagnosed with this condition was 46.
NHS Forth Valley	NHS Forth Valley operates an interdepartmental Multi Disciplinary Team (MDT) approach to management of Functional Neurological Disorders. This Team meets regularly alongside their direct care of people with FND. Members include Neurology, Psychiatry, Clinical Psychology, Physiotherapy, Occupational Therapy, Primary Care Physicians, and others.	Tests are not used to diagnose FND (no such tests exist), but rather to exclude potential alternative diagnoses if appropriate in an individual patient's case.	All treatment plans are individualised to the patient's requirements. This includes information support, medications, psychological interventions, and physical therapy as relevant.	We do not collect this date. As a result, we are obliged to respond to your request in terms of section 17 of the Freedom of Information (Scotland) Act 2002: Information not held.
NHS Greater Glasgow and Clyde.	The Adult Neurology service in NHS Greater Glasgow & Clyde (NHSGGC) sees patients presenting to neurology and medical services with presentations in keeping with functional /conversion disorder / non-epileptic attack disorder.	Depending upon presentation, patients are often assessed by a combination of clinical history, neurological examination, imaging of the relevant part of the nervous system, EMG and EEG studies. The most useful test	The most important part of treatment is explanation of the diagnosis, the reasons for the diagnosis, and explanation of the psychosocial and mental health circumstances that lead to functional / conversion disorder and non-epileptic attack disorder.	This is difficult to quantify, as often patients already have existing mental health illness, or may have a combination of other medical / neurological illness accompanied by functional / conversion disorder. Patients may be seen

NHS Trust/ Health board	Please report the number of NHS Functional neurological disorder/conversion disorder/functional seizure specific departments or centres in your Trust	Please report the most common diagnostic tests used in your Trust to diagnose patients with functional neurological disorder/conversion disorder/functional seizures in the last 5 years	Please report the most common treatments used in your Trust to support patients with Functional neurological disorder/conversion disorder/functional seizures in the last 5 years	Please report the number of patients in your Trust diagnosed with Functional neurological disorder/conversion disorder/functional seizures in the last 5 years
	Patients are seen on all sites in NHSGGC that provide acute medical care. Within the children's neurological service, we see children and young people with functional neurological disorders. When we make this diagnosis we will see them with the liaison psychiatry team who will lead on the therapeutic management.	for a functional neurological disorder is the video of the event, a specialist seeing an event and clinical examination of the individual. These are the ways to make a positive diagnosis. Other tests such as vEEG may be used to help demonstrate the events are not epileptic in nature.	Following the above, patients are offered assessment and treatment via a range of relevant services in NHSGGC including appropriate mental health services and rehabilitation services. This is in keeping with other patients presenting with other illness in NHSGGC. The treatments will be multi-disciplinary including Child and Adolescent Mental Health Services (CAMHS), neurology and sometimes physiotherapy and occupational therapy, depending on the nature of the symptoms.	across many different departments. Many individuals with neurological conditions can also have functional symptoms during their disease course. There is prior epidemiological data relevant to Scotland available via prior publications by neurology colleagues in Edinburgh.
NHS Borders	NHS Borders does not have a specific department or centre for Functional Neurological Disorder / Conversion Disorder / Functional Seizure Disorder. We have a Neurology Service that operates predominantly from the Borders General Hospital.	Clinical assessment is the most important diagnostic used in NHS Borders to diagnose patients with Functional Neurological Disorder / Conversion Disorder / Functional Seizure Disorder. A detailed understanding of past history, all symptoms and positive signs on examination are also common diagnostic tests that are used. These are supplemented with MRI, EEG,	A detailed discussion is held with NHS Borders patients diagnosed with Functional Neurological Disorder / Conversion Disorder / Functional Seizure Disorder and they are given an explanation about their condition. Some patients may be referred to the FND team in Edinburgh (possibly for CBT), and some patients are referred to Liaison Psychiatry if appropriate.	This information is not held electronically. The data may be held in a patient's record, but to extract this data would require a manual trawl of all patient records and the cost of carrying out this work would exceed the limit set in the Fees Regulations of the Freedom of Information (Scotland) Act 2002 and under Section 12 we are not required to provide.

NHS Trust/ Health board	Please report the number of NHS Functional neurological disorder/conversion disorder/functional seizure specific departments or centres in your Trust	Please report the most common diagnostic tests used in your Trust to diagnose patients with functional neurological disorder/conversion disorder/functional seizures in the last 5 years	Please report the most common treatments used in your Trust to support patients with Functional neurological disorder/conversion disorder/functional seizures in the last 5 years	Please report the number of patients in your Trust diagnosed with Functional neurological disorder/conversion disorder/functional seizures in the last 5 years
		videos, video telemetry, and other tests as required.		
NHS Orkney	Please be advised that NHS Orkney is a small remote and rural health board which operates one hospital – The Balfour. The Balfour Hospital does not have any functional neurological disorder/conversion disorder/functional seizure specific departments.	NHS Orkney provides a range of care for patients diagnosed with Functional Neurological disorder provided by allied healthcare workers, psychology and psychiatry. Patients will be seen at NHS Grampian for diagnostic services, outpatient consultations, diagnostic explanations and follow ups. NHS Grampian also has an inpatient facility to provide assessment, investigation and management for NHS Orkney patients diagnosed with a functional neurological disorder.	NHS Orkney provides a range of care for patients diagnosed with Functional Neurological disorder provided by allied healthcare workers, psychology and psychiatry. Patients will be seen at NHS Grampian for diagnostic services, outpatient consultations, diagnostic explanations and follow ups. NHS Grampian also has an inpatient facility to provide assessment, investigation and management for NHS Orkney patients diagnosed with a functional neurological disorder.	NHS Orkney does not hold a list of patients diagnosed with functional neurological disorder. NH Orkney has run a check on the board administered GP practice data systems and has not identified any patients diagnosed with FND.
NHS Highland	NHS Highland have not done a specific epidemiological analysis, however FNDs are quite common, and this is a spectrum of symptoms as on many occasions they may co-exist with an organics neurological problem. For this reason, the exact numbers are unknown although the consensus at the Neurology	Clinical and neurological examination, then depending on clinical syndrome, further exams including nerve conduction studies or MRI of the brain/spine to rule-out organic causes. Psychology and mental health team input is also needed	Physiotherapy, rehabilitation, mental health and psychological support There is a multidisciplinary team and FND MDT meeting on a monthly basis to review complex cases.	We don’t have the exact numbers, although they are prevalent. There is a spectrum of severity of this disorder ranging from mild and overlapping syndromes to the pure and severe ones, so this may difficult the epidemiological characterisation.

NHS Trust/ Health board	Please report the number of NHS Functional neurological disorder/conversion disorder/functional seizure specific departments or centres in your Trust	Please report the most common diagnostic tests used in your Trust to diagnose patients with functional neurological disorder/conversion disorder/functional seizures in the last 5 years	Please report the most common treatments used in your Trust to support patients with Functional neurological disorder/conversion disorder/functional seizures in the last 5 years	Please report the number of patients in your Trust diagnosed with Functional neurological disorder/conversion disorder/functional seizures in the last 5 years
	department is that they are quite prevalent, and perhaps 20 of the patients seen at Neurology clinics may present in some degree with some functional symptoms. However, a pure functional neurological disorder/conversion disorder may happen in 5-10%. Regarding functional seizures, this perhaps may happen in 15% of our patients, and even people with chronic epilepsy or learning disability may present with both real seizures and functional ones			
NHS Western Isles	NHS Western Isles do not have a department/centre in our Health Board.	Patients from NHS Western Isles are referred to NHS Greater Glasgow & Clyde Adult Neurology service	Patients from NHS Western Isles are referred to NHS Greater Glasgow & Clyde Adult Neurology service	<5 per year
NHS Fife	NHS Fife does not have specific FND department or centres, all patients are seen within the Neurology department.	The most common diagnostic tests used in NHS Fife are physical examination, scans (typically MRI and CT), EEG (brain wave recording), vEEG monitoring and home video records.	The most common treatments used in NHS Fife are explanation of the diagnosis, physiotherapy, psychology and occasional referral to neuropsychiatry.	NHS Fife does not hold the information requested, as outpatient diagnosis is not recorded within our Patient Administration System, this is also not a mandatory reporting field in Scottish Government returns.
NHS Dumfries and Galloway	0	Clinical examination	Education/Psychology	approx. 10 patients per month

NHS Trust/ Health board	Please report the number of NHS Functional neurological disorder/conversion disorder/functional seizure specific departments or centres in your Trust	Please report the most common diagnostic tests used in your Trust to diagnose patients with functional neurological disorder/conversion disorder/functional seizures in the last 5 years	Please report the most common treatments used in your Trust to support patients with Functional neurological disorder/conversion disorder/functional seizures in the last 5 years	Please report the number of patients in your Trust diagnosed with Functional neurological disorder/conversion disorder/functional seizures in the last 5 years
NHS Tayside	NHS Tayside has no dedicated service / clinic for functional neurological disorders (FND) at present. There was a monthly clinic until clinician retirement in July 2021. We are currently reviewing resources with a plan to re-instating this clinic but do not have a timescale for this at present	FND would be diagnosed on clinical presentation and demonstration of functional signs of examination. In those with functional seizures, video recordings of events are very helpful, however if this is not possible, a provoked EEG may be under taken.	For FND/functional seizures, the most common management plan would be patient education, management of any contributory factors to their presentation, MDT input with input from physiotherapy, occupational therapy, and psychology, dependent on presentation	Most patients are seen in the out-patient setting either at diagnosis or for follow up. Unfortunately it is not possible to identify numbers of patients with FND in the out-patient setting.
NHS Lothian	You can see all our services on Refhelp - Functional Neurological Disorder (FND) – RefHelp (nhslothian.scot)	Its a clinical diagnosis based on positive clinical feature- MRI and EEG routinely used to supplement	See Refhelp	Records not kept
NHS Ayrshire and Arran	The Adult Neurology service in NHS Ayrshire & Arran (NHSAA) Health Board sees patients presenting to neurology and medical services with presentations in keeping with functional / conversion disorder / non-epileptic attack disorder. Patients are seen on all sites in NHSAA that provide acute medical care.	Depending upon their clinical presentation, patients are often assessed by a combination of clinical history, neurological examination, imaging of the relevant part of the nervous system, EMG and EEG studies, and any other appropriate tests.	The most important part of treatment is explanation of the diagnosis, the reasons for the diagnosis, and explanation of the psychosocial and mental health circumstances that lead to functional / conversion disorder and non-epileptic attack disorder. Following the above, patients are offered assessment and treatment via a range of relevant services in NHSAA including appropriate mental health services and rehabilitation services. This is in keeping with	There is prior epidemiological data relevant to Scotland available via prior publications by neurology colleagues in Edinburgh (Jon Stone, et al). Data on the incidence of non-epileptic seizures is available via publications by Razvi et al, based on epidemiological data in NHSAA. *NHS Ayrshire & Arran does not centrally record this information.

NHS Trust/ Health board	Please report the number of NHS Functional neurological disorder/conversion disorder/functional seizure specific departments or centres in your Trust	Please report the most common diagnostic tests used in your Trust to diagnose patients with functional neurological disorder/conversion disorder/functional seizures in the last 5 years	Please report the most common treatments used in your Trust to support patients with Functional neurological disorder/conversion disorder/functional seizures in the last 5 years	Please report the number of patients in your Trust diagnosed with Functional neurological disorder/conversion disorder/functional seizures in the last 5 years
			other patients presenting with other illness in NHSAA	
NHS Lanarkshire	The Adult Neurology service in NHS Lanarkshire sees patients presenting to neurology and medical services with presentations in keeping with functional /conversion disorder/non-epileptic attack disorder. Patients are seen on all three of our acute sites – University Hospital Hairmyres, University Hospital Monklands and University Hospital Wishaw.	Which diagnostics tests are undertaken depends upon the presentation of each individual patient. Patients are assessed by a combination of clinical history, neurological examination, imaging of the relevant part of the nervous system, EMG and EEG studies.	The most important part of treatment is the conversation with the patient explaining the diagnosis, the reasons for the diagnosis, and of the psychosocial and mental health circumstances that lead to functional/conversion disorder and non-epileptic attack disorder. Following the conversation, patients are offered assessment and treatment through a range of relevant services including appropriate mental health services and rehabilitation services.	It is difficult to quantify the number of patients diagnosed with Functional neurological disorder/conversion disorder/functional seizures in Lanarkshire over the last 5 years. This is due to patients already having existing mental health illness, or a combination of other medical/neurological illness accompanied by functional/conversion disorder.
NHS Grampian	Functional neurological disorders is diagnosed and managed in NHS Grampian in the Neurology Department and the service includes collaboration with primary care, allied healthcare professionals in the hospital and community, rehabilitation team at Horizon's, liaison	Diagnostic investigations are targeted to the individual patient, their presentation, unique symptoms and no single diagnostic test is indicated or routinely performed for this condition. No other data available.	Treatments/management is targeted to the individual patient's needs. We have no data on the most common treatments for this patient group; s.17 of the Act refers – Information not held.	We do not have data on this; s.17 of the Act refers – Information not held. However from previous research it is suggested that at least 30% of general neurology consultations would be due to FND, this would also apply to our service.

NHS Trust/ Health board	**Please report the number of NHS Functional neurological disorder/conversion disorder/functional seizure specific departments or centres in your Trust**	**Please report the most common diagnostic tests used in your Trust to diagnose patients with functional neurological disorder/conversion disorder/functional seizures in the last 5 years**	**Please report the most common treatments used in your Trust to support patients with Functional neurological disorder/conversion disorder/functional seizures in the last 5 years**	**Please report the number of patients in your Trust diagnosed with Functional neurological disorder/conversion disorder/functional seizures in the last 5 years**
	psychiatry and neuropsychology.			
Cwm Taf Morgannwg University Health Board	Doesn't hold this information	Doesn't hold this information	Doesn't hold this information	Doesn't hold this information
Powys Teaching Health Board	PTHB does not keep a register of patients with this diagnosis. Our community patient records do not allow us to search for patients by condition.	PTHB do not have any neurologists and therefore do not diagnose these conditions.	Our community neuro rehabilitation and speech and language therapy teams provide therapy and take a person-centred approach to treating people with FND. They are supported by a cognitive behavioural therapist from the community mental health team. We do not have any specific psychological support for pathways with FND, but people can access core community mental health services for support for any specific issues around anxiety and depression.	PTHB does not keep a register of patients with this diagnosis. Our community patient records do not allow us to search for patients by condition.
NHS England	NHS England is not wholly responsible for the commissioning of all neurology services and is only responsible for commissioning specialised neurology services. The other neurology services	NHS England does not hold this information.	The three most common procedures (in order of magnitude) over the past 5 years (2017-18 to 2021-22), for inpatients whose primary diagnosis was functional neurological disorder/conversion disorder/functional seizures as defined by ICD10 codes F444,	NHS England does not hold a registry or diagnostic database of individual patients diagnosed with functional neurological disorder/conversion disorder/functional seizures and we are therefore unable to advise how many patients

NHS Trust/ Health board	Please report the number of NHS Functional neurological disorder/conversion disorder/functional seizure specific departments or centres in your Trust	Please report the most common diagnostic tests used in your Trust to diagnose patients with functional neurological disorder/conversion disorder/functional seizures in the last 5 years	Please report the most common treatments used in your Trust to support patients with Functional neurological disorder/conversion disorder/functional seizures in the last 5 years	Please report the number of patients in your Trust diagnosed with Functional neurological disorder/conversion disorder/functional seizures in the last 5 years
	are commissioned by Integrated Care Boards (ICBs) (previously Clinical Commissioning Groups (CCGs)). The below information is provided from 24 specialised neuroscience centres in England and relates to the services commissioned directly by NHS England.		F445, F446 and F447, are: U221: ELECTROENCEPHALOGRAPH TELEMETRY A841: ELECTROENCEPHALOGRAPHY NEC A559: UNSPECIFIED DIAGNOSTIC SPINAL PUNCTURE Please note that this information is only a subset of patients with this diagnosis who have attended hospital in this time period commissioned by NHS England. It does not include patients who may have attended services commissioned by ICBs.	have been diagnosed in the past 5 years. The number of patients over the past 5 years seen as an inpatient with a primary diagnosis of functional neurological disorder/conversion disorder/functional seizures as defined by ICD10 codes F444, F445, F446 and F447 are outlined below. This cannot be derived for patients seen in an outpatient setting due to the poor levels of diagnosis coding in outpatients. The data below is the sum of unique patient IDs attending in each year. 2017/18: 514 2018/19: 742 2019/20: 909 2020/21: 602 2021/22: 892 Please note that this is not the total patient numbers attending hospital and is only a subset of patients with this diagnosis

NHS Trust/ Health board	**Please report the number of NHS Functional neurological disorder/conversion disorder/functional seizure specific departments or centres in your Trust**	**Please report the most common diagnostic tests used in your Trust to diagnose patients with functional neurological disorder/conversion disorder/functional seizures in the last 5 years**	**Please report the most common treatments used in your Trust to support patients with Functional neurological disorder/conversion disorder/functional seizures in the last 5 years**	**Please report the number of patients in your Trust diagnosed with Functional neurological disorder/conversion disorder/functional seizures in the last 5 years**
				who have attended hospital in this time period commissioned by NHS England. It does not include patients who may have attended services commissioned by ICBs.
Cardiff and Vale	0	Selfie video, EEG, MRI, history	No treatments as there is not currently a psychology service provided to these patients	In completing a search for the information requested, Cardiff and Vale University Health Board (the UHB) has confirmed that this information is not centrally recorded or collated.
Northern Health and Social Care Trust	Unable to quantify as outpatients is not coded on the Trust's information system.	In terms of investigation, again this is quite patient specific and depends also on how confident you are with the diagnosis, patient anxiety etc.	Treatment is in conjunction with OT, psychology, OT and social workers.	Unable to quantify as outpatients is not coded on the Trust's information system.
Aneurin Bevan Health Board	None	Relevant tests to exclude organic pathology, primarily MRI scans, brain, EEG, blood tests and ECG.	Very limited specific treatments available. Support and training in sensory grounding techniques is provided by Epilepsy Specialist Nurses.	The Health Board is unable to provide this information as it is not recorded centrally.
Hywel Dda University Health Board	Patients diagnosed with or undergoing testing for FND are referred to Swansea Bay University Health Board (SBUHB) and are managed according to the specialist advice from that Health Board.			

NHS Trust/ Health board	Please report the number of NHS Functional neurological disorder/conversion disorder/functional seizure specific departments or centres in your Trust	Please report the most common diagnostic tests used in your Trust to diagnose patients with functional neurological disorder/conversion disorder/functional seizures in the last 5 years	Please report the most common treatments used in your Trust to support patients with Functional neurological disorder/conversion disorder/functional seizures in the last 5 years	Please report the number of patients in your Trust diagnosed with Functional neurological disorder/conversion disorder/functional seizures in the last 5 years
Swansea Bay University Health Board (SBUHB)	The Health Board does not have any specific departments or centres for FND/ conversion disorder/ functional seizures.	Most patients are diagnosed based on the history and clinical examination, and increasingly with the help of patient videos (e.g. of seizures or abnormal movements). Investigations are used alongside this and in order of importance; · MRI scans – brain +/- spine · Electroencephalogram (EEG) · Nerve conduction studies · Lumbar puncture	The only definitive treatment that has been offered within the health board was psycho-educative workshops for dissociative seizures. A small number of patients have had cognitive behavioural therapy (CBT) and eye movement desensitization and reprocessing (EMDR) treatment.	I can confirm that this information is not held centrally.

Appendix 17: Theme coding by participant

Theme coding by participant (split across two tables)

Participant	Theme 1: The impact of FND	FNDs impact on the self	FNDs impact on the family unit	Impact on friendships	FNDs Impact on healthcare workers	Theme 2: Support: ‘ it takes a village’	Support received from healthcare workers	Support from the community	Support from caregivers	Support from family and loved ones	Support from school and work
PT1	9	3	6	0	0	20	11	5	1	3	0
PT2	4	2	2	0	0	7	3	2	2	0	0
PT3	15	10	3	2	0	19	12	3	1	3	0
PT4	21	14	7	0	0	30	21	0	4	5	0
PT5	3	3	0	0	0	21	13	5	0	1	2
PT6	11	7	0	4	0	33	22	5	0	6	0
PT7	4	4	0	0	0	20	12	8	0	0	0
PT8	16	15	1	0	0	49	36	2	1	4	6
PT9	14	8	0	6	0	40	27	6	0	7	0
PT10	4	4	0	0	0	15	10	1	0	1	3
CG1	3	2	0	1	0	25	17	2	2	3	1
CG2	16	9	6	1	0	35	8	1	17	6	3
CG3	11	8	3	0	0	53	15	5	29	3	1
CG4	21	12	9	0	0	40	14	12	8	1	5
CG5	16	9	6	1	0	32	14	4	11	3	0

Participant	Theme 1: The impact of FND	FNDs impact on the self	FNDs impact on the family unit	Impact on friendships	FNDs Impact on healthcare workers	Theme 2: Support: ‘ it takes a village’	Support received from healthcare workers	Support from the community	Support from caregivers	Support from family and loved ones	Support from school and work
CG6	8	5	3	0	0	36	7	7	18	2	2
CG7	14	6	6	2	0	39	8	12	17	1	1
CG8	0	0	0	0	0	26	11	1	5	0	9
HCW1	0	0	0	0	0	8	5	2	1	0	0
HCW2	7	3	1	0	3	41	36	1	3	1	0
HCW3	0	0	0	0	0	19	13	1	5	0	0
HCW4	0	0	0	0	0	26	26	0	0	0	0
HCW5	4	2	0	0	2	18	13	3	0	0	2
HCW6	1	0	0	0	1	25	18	5	2	0	0
HCW7	1	0	0	0	1	9	7	1	1	0	0
HCW8	6	2	0	0	4	27	26	1	0	0	0
HCW9	1	0	0	0	1	14	12	0	0	1	1
HCW 10	0	0	0	0	0	16	12	2	1	0	1

Participant	Theme 3: Life after diagnosis	Adapting to the new normal	Treatments: the road to nowhere	Accepting and believing the ‘ FND label’	Theme 4: The art of communication	The patient-professional relationship	Information sharing	Communication between healthcare workers and services	Theme 5: Resources: the barrier to effective and timely care	Waiting times	Barriers to accessing resources	Total
PT1	32	7	15	10	24	15	9	0	10	5	5	95
PT2	8	1	4	3	18	9	9	0	12	8	4	49
PT3	16	8	3	5	29	19	9	1	8	3	5	87
PT4	21	12	7	2	36	22	11	3	7	0	7	115
PT5	4	0	4	0	14	9	4	1	4	2	2	46
PT6	11	4	7	0	35	25	9	1	25	11	14	115
PT7	15	2	8	5	13	7	5	1	5	3	2	57
PT8	28	9	14	5	29	16	11	2	21	5	16	143
PT9	39	11	21	7	29	16	12	1	13	3	10	135
PT10	3	0	3	0	22	9	12	1	2	2	0	46
CG1	5	0	5	0	15	5	10	0	18	10	8	66
CG2	11	0	11	0	16	8	8	0	9	4	5	87
CG3	28	0	27	1	24	15	9	0	13	3	10	129
CG4	47	16	23	8	26	14	12	0	4	4	0	138
CG5	14	4	10	0	17	9	7	1	4	2	2	83
CG6	24	8	13	3	11	7	4	0	2	0	2	81
CG7	19	5	14	0	26	14	12	0	10	4	6	108
CG8	19	1	16	2	12	5	7	0	6	2	4	63
HCW1	14	0	12	2	15	11	4	0	12	3	9	49

Participant	Theme 3: Life after diagnosis	Adapting to the new normal	Treatments: the road to nowhere	Accepting and believing the ‘ FND label’	Theme 4: The art of communication	The patient-professional relationship	Information sharing	Communication between healthcare workers and services	Theme 5: Resources: the barrier to effective and timely care	Waiting times	Barriers to accessing resources	Total
HCW2	9	0	7	2	23	11	10	2	10	2	8	90
HCW3	13	1	11	1	18	13	4	1	5	0	5	55
HCW4	5	1	4	0	17	13	4	0	2	0	2	50
HCW5	11	2	7	2	16	6	10	0	6	3	3	55
HCW6	17	0	13	4	47	27	15	5	10	1	9	100
HCW7	6	0	4	2	14	9	4	1	15	4	11	45
HCW8	14	3	7	4	35	25	4	6	14	6	8	96
HCW9	17	1	13	3	17	11	4	2	8	1	7	57
HCW 10	8	0	5	3	25	12	10	3	8	1	7	57

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